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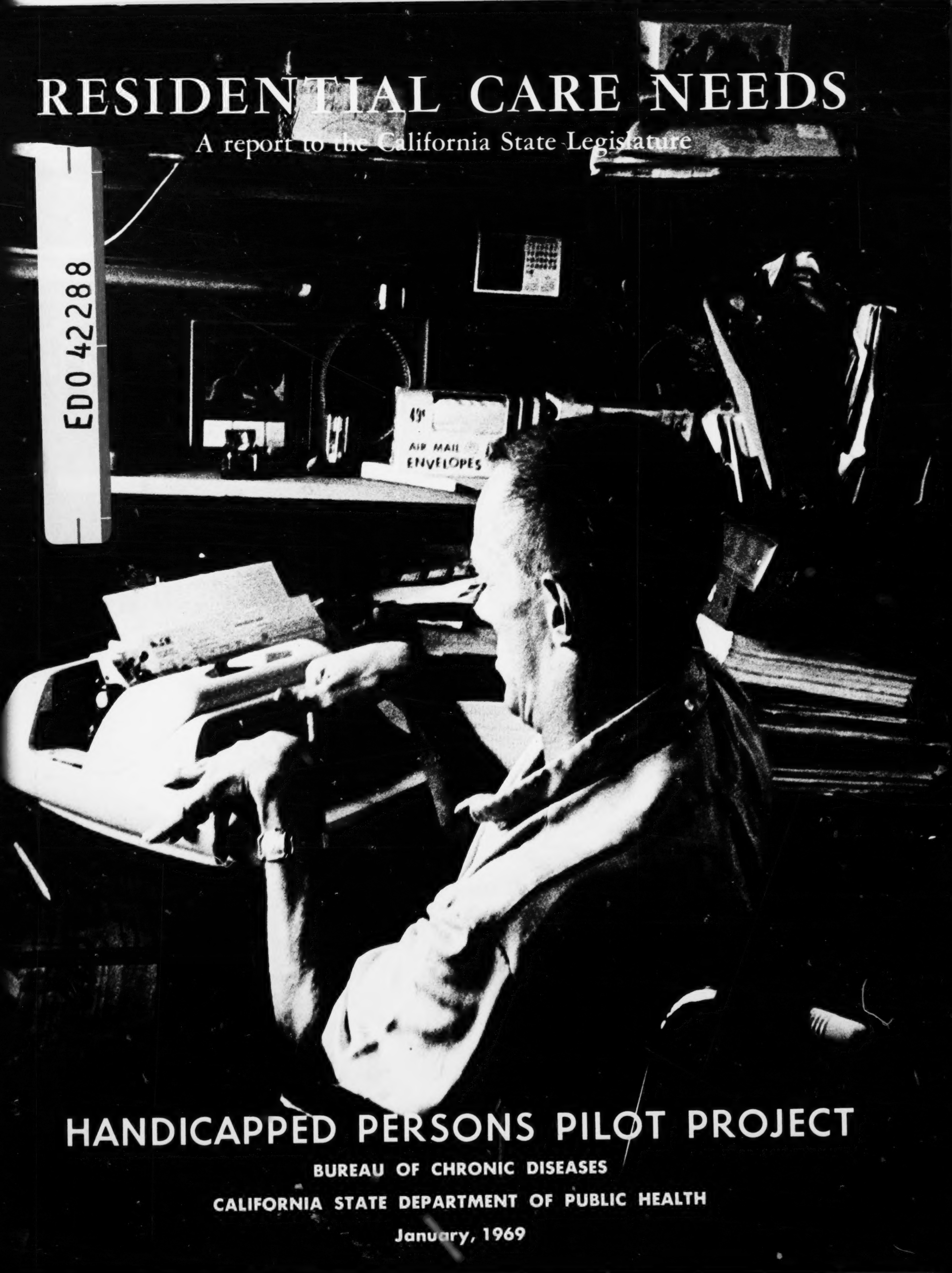
ABSTRACT

A study of 115 mentally normal persons with severe physical handicaps indicated that existing service and living arrangement programs were inadequate. Results suggested the following: establishment of a coordinating state agency and local supervisory teams of nurses and social workers; arrangement of a variety of living accommodations, including temporary care for persons ordinarily living at home; and provision of funds for equipment and home modification. Further recommendations called for a health oriented community agency stressing preventive care, attendant care programs, and protectorship services. Also needed were flexible interpretation of regulations governing existing programs and case management developing and utilizing the abilities and talents of the handicapped. (JD)

RESIDENTIAL CARE NEEDS

A report to the California State Legislature

ED0 42288



HANDICAPPED PERSONS PILOT PROJECT

BUREAU OF CHRONIC DISEASES
CALIFORNIA STATE DEPARTMENT OF PUBLIC HEALTH
January, 1969

ED0 42288

HANDICAPPED PERSONS
PILOT PROJECT

RESIDENTIAL CARE NEEDS

A Report to the California State Legislature

January, 1969

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January 2, 1969

Hon. Ronald Reagan, Governor of California
Sacramento
Hon. Hugh M. Burns, President pro Tempore
State Senate, Sacramento
Hon. Robert T. Monagan, Speaker
State Assembly, Sacramento

Gentlemen:

The California Legislature, by Chapter 1419-1965, created the Handicapped Persons Pilot Project to find feasible solutions to the long-term residential care needs of severely physically handicapped persons of normal mentality. Working closely with representative groups of handicapped persons and their families, the project staff was able to define the nature and extent of their problems and find reasonable solutions based on individual needs and available resources.

This report contains the project findings as well as recommendations to help alleviate the problems revealed. Included in the report is a description of the nature and extent of the problems these people face, an explanation of the methods used by staff to find solutions to many of these problems and illustrations of benefits that can accrue to the individuals, their families and communities.

Implementation of these recommendations by appropriate legislation will greatly enhance the living potential of handicapped people.

Respectfully submitted,

Louis F. Saylor

Louis F. Saylor, M.D.
Director of Public Health

HANDICAPPED PERSONS PILOT PROJECT

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ACKNOWLEDGEMENT

Without the assistance and cooperation of many organizations and people, the staff would have been unable to carry out the provisions of Senate Bill No. 934. We especially appreciate the assistance of the Advisory Committee whose counsel was so helpful in implementing and carrying out the Pilot Project. Many voluntary and official health and social agencies contributed. We particularly thank the Long Beach City Health Department and the Easter Seal Societies of Los Angeles and Sacramento which helped materially in the implementation of the local programs.

The cooperative spirit of the participants, their families and friends made it possible for us to study the complex and varied problems which face this group of people and to devise methods of alleviating them.

This report could not have been realized without the clerical assistance of local and Bureau staffs, the Report Preparation Unit and the Duplicating Section of the Department. Special acknowledgement is made of the service of Mrs. M.E. Laughlin and Mr. Le Mar Hoaglin.

We express our sincere thanks to the above and all others who assisted on this project.

SUMMARY

WHAT WAS IT?

The Handicapped Persons Pilot Project was a study authorized by the State Legislature to determine residential care needs of severely handicapped persons of normal mentality. "Residential care" was used in the broadest sense to denote not a special institution to house handicapped persons, as a state hospital houses the mentally ill, but to embrace all types of services and living arrangements appropriate for individuals who are severely physically handicapped, but of normal mentality. "Residential care" thus included a flexible range of housing situations and a determination of which care services were essential and appropriate for the well-being of the individual handicapped person.

WHOM DID IT SERVE?

A small group of mentally normal children and adults, selected from and representative of approximately 10,000 Californians, who are so handicapped that they must depend upon help from others to carry out such routine daily functions as eating, dressing and moving about.

WHAT CAN BE DONE?

Results show that most handicapped people of normal mentality do not need, nor do they desire, institutional placement. Rather, with the provision of medical supervision, attendant care, nursing, counseling, and all forms of "residential care" most can function well in their present independent living arrangements. For a few others, special housing, such as a protective facility may be necessary. The longer this latter solution is avoided, however, the happier and more independent the person, and the more economical his care.

FINDINGS AND RECOMMENDATIONS

At the present time approximately 10,000 Californians under the age of 65, severely physically handicapped but of normal mentality, need some form of residential care services. Probably no more than 2,000 have critical needs not being met at any one time. Within the 10,000 are represented all socioeconomic levels. Their common characteristics, the range and degree of their needs and their dependence on others for life itself make them a distinct group for which the combination of existing assistance programs is inadequate.

There is no one agency, program or source which now meets the multiple, complex and varied needs of the physically handicapped. The individual (or his family) has to seek out and piece together the various services needed, or do without. Many do not have the inner resources and knowledge to do this.

> *It is recommended that a State program be established with responsibility to see that adequate services are provided in the place of residence to care for the comprehensive needs of the severely physically handicapped of normal mentality, drawing upon all available government, voluntary and private resources in the community.*

When a handicapped person or someone on his behalf attempts to piece together the various services needed, many barriers block the way, delaying or making it impossible for him to receive adequate care. Some barriers lie within the family or handicapped individual; others are the result of the existing system for providing assistance.

The problems of the handicapped and their families are multiple and complex. Health problems are so closely intertwined with social problems that lasting solutions to one cannot be secured without coincidental consideration of the other. Crisis is apt to follow upon crisis at frequent intervals until finally few families are able to handle them without outside help other than monetary. With proper ongoing care many crises, whether medical, social or both, can be avoided.

Of the help available to the handicapped, much goes unused. To determine their needs, to find resources, to supply and coordinate them takes the knowledge and skill of both health and social service professionals.

> *Establish local supervisory teams of nurse and social worker to determine the needs, to find sources of necessary services and to see that they are coordinated, delivered and changed as needed on an individual case basis.*

Most handicapped persons can and do live independently in the community and express a strong desire to continue doing so. A variety of living arrangements makes this possible and feasible. More could and would live at home if there were better and easier means of providing occasional respite for the family or emergency substitute care.

> *Arrange for a variety of living accommodations in the community appropriate to and suitably adapted to the needs of the handicapped and in which comprehensive residential care services can be rendered.*
>
> *Provide for the temporary shelter and residential care of those handicapped persons who ordinarily live at home.*

Housing presents a problem because of architectural barriers and prohibition against alterations, and because rental properties, especailly low rental properties, are apt to be substandard - often dangerously so for the handicapped. Also, lack of or inadequate equipment reduces mobility of the handicapped.

> *Provide funds to modify dwellings and repair or purchase equipment necessary to maintain a handicapped person in his own home or to preserve the integrity of his family.*

All handicapped persons live under the constant shadow of a medical crisis or emergency and must have ready access to medical and paramedical services.

Medical care for acute conditions is as readily available to the handicapped as to others, but ongoing care and adequate paramedical care are difficult for them to obtain. Preventive care is woefully inadequate.

The group as a whole already has been through extensive and expensive physical medicine and rehabilitation services. Through these services they have been brought to their maximum level of physical functioning. Without follow-up and ongoing care many deteriorate rapidly and unnecessarily. As a result many require and now obtain repeated rehabilitation.

> *That case management and ongoing residential care services be provided by a health oriented community agency of high quality, such as a coordinated home care or other agency, staffed with a well-trained professional group of paramedical and social work members accustomed to functioning as a team.*
>
> *That care include and emphasize preventive care.*

Each handicapped person is dependent upon help from someone else and often upon a mechanical device as well for at least some major activity of daily living, and therefore for life itself.

For the most part, this help can be and is given by nonprofessional persons. Those now giving such care are essentially untrained, unsupervised, inadequately paid and responsible to no one but the handicapped person or his family. The care itself is often inadequate, inappropriate, dangerous and likely to lead to unnecessary complications.

> *Provide reasonable attendant-type care, as needed, to be given by adequately trained and supervised nonprofessional, agency-hired personnel.*

These handicapped persons have alert, active minds, normal ambitions, normal emotional needs and reactions, normal abilities for creativity and normal desires for mental stimulation, occupation, recreation and community life.

Individual characteristics - initiative, perserverence, education, independence, ingenuity - seem to influence what the person can do for himself and the range of his activities, often as much as his physical condition. The level of education attained is generally related to the age at which the handicapping condition occurred. Many have the ability and strong desire for more education but are unable to obtain it.

For all of them the range of activities is necessarily restricted because no one has found a way to bring services into the residence; for many it is unnecessarily restricted. This plight is made worse by great barriers to transportation encountered by the handicapped. The result is that monotony, boredom, lack of mental stimulation often make life nearly unbearable.

Some handicapped are capable of increased function, even to the point of employability, when they are given counseling, training and other assistance. When they seek help they encounter difficulty, often because their physical disability seemingly makes the prospect of employment impossible. Often opportunities for employment are automatically cut off even for those who are employable.

Too often handicapped persons or their families lack the knowledge of what is needed, what services are available and how to seek out and coordinate them. When services are not available, it is equally difficult to find alternate solutions.

> *That flexibility in interpretation of regulations governing Federal, State and local programs be sought for this group.*

> *That through case management or supervision, effort be made to discover suitable means of developing and utilizing the talents and abilities of the handicapped.*

For various reasons related to their handicap, this group is pecularily susceptible to fraudulent practices and often at the mercy of the unscrupulous, the unmerciful, the unreliable, even the violent. Some, though mentally capable of managing their business affairs, are physically incapable of doing so.

The chief concern of the parents and of many of the handicapped themselves is for the future. When parents are no longer there, or no longer able to care for them, who will see that they get the care without which they cannot exist?

> *Develop protectorship services to guard those unable to guard themselves against abuse and unscrupulous practices, and to accept the responsibility for the provision of care when no one else is able to do this.*

BENEFITS

The Pilot Project showed that many benefits accrue from a program such as that recommended here and described in detail in the section "Proposed Program."

- The vast majority of the handicapped will be able to live in their own homes where they prefer to live and generally fare better. They will receive as wide a range of services and as satisfactory care in the home as in an institution. By provision of temporary or respite care, some handicapped now living in institutions can be returned to their homes.
- Case management and coordination of services:
  - Will make possible full utilization of existing community resources; little additional care then needs to be supplied.
  - Will facilitate delivery of the full range of services needed by the individual,
  - Will insure continuity of care, and
  - Will provide outside professional counsel and guidance for the family.
- Continuing paramedical and preventive care will greatly reduce physical deterioration and the occurrence of medical crises.
- Ongoing individual counseling will greatly reduce the likelihood of social deterioration.
- Protectorship services will prevent abuse and misuse of the handicapped and will assure them continuing care when their families can no longer provide it.
- Development of activities for the individual to the maximum extent possible will improve the lot of the handicapped and his family.
- Promotion of education and training will increase the degree of independence, even to the point of employability for some.

Of the possible alternatives the proposed programs can provide the full range of services needed by the severely physically handicapped of normal mentality at the lowest cost.

> ***It is recommended that the program for the handicapped be initiated on a small scale to allow orderly recruitment of adequately trained and experienced professional staff and assure the well ordered development of procedures. An appropriation of $350,000 will permit the establishment and first year operation of the State supervisory staff, together with the development of service programs in four areas. Extension to other areas in California should follow demonstration of need.***

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INTRODUCTION

In recent years the California Legislature has devoted considerable attention to problems of the physically handicapped, their families and communities. It has adopted measures related to financial assistance, educational and vocational programs, and physical rehabilitation and diagnostic services. In 1965, a study authorized by the Senate Fact Finding Committee on Labor and Welfare reported on the need for residential care of the severely physically handicapped of normal mentality. This study noted that:

> "... county hospital geriatric wards and boarding and nursing homes for the aging become the permanent residences of disabled youths in their teens and twenties; residential educational facilities keep the handicapped long past the time required for profitable educational purposes; day care facilities are used when only full-time residential services would meet the need; specialized residential institutions in the few places where they exist are prohibitively overburdened with admission requests or inadequate budgets. Thus existing community resources are diverted from their main, their most efficient and their usually heavily demanded purposes simply because more appropriate alternative sources of residential care services do not exist. The costs of doing so, on both humane and fiscal bases, is (sic) undoubtedly extravagant..."[1]

It further noted that little was known about the specific care needs of severely handicapped, mentally normal persons. An estimate indicated that approximately 500 people meeting the criteria of the study were in urgent need of long-term residential care services; some because their families lacked financial resources, others because of a shortage of appropriate private or public facilities. Many more had immediate needs, but were not in such dire circumstances; however, most handicapped persons and their families, not in need of immediate services, were apprehensive about the future, when the aging or death of parents or exhaustion of family resources would threaten or disrupt their care. No formal program charged with the responsibility of looking after them existed in the State.

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[1] Senate Fact Finding Committee on Labor and Welfare, Final Report on the Need for Residential Care of Severely Physically Handicapped Persons of Normal Mentality, Sacramento, 1965, p. 13.

To alleviate these conditions, the Senate considered the following alternatives: to build new facilities; to convert existing facilities; to expand the Aid to the Totally Disabled Program (ATD); to purchase residential care services from private sources or to establish a pilot project to obtain a more accurate estimate of the numbers in need, more detailed information on the extent of the need, the cost and how best to provide these needed services. By unanimous decision, the Legislature chose the last alternative and established a four-year Handicapped Persons Pilot Project[1] in the State Department of Public Health to conduct studies in two areas of the State to:

- determine the number of physically handicapped persons of normal mentality in need of residential care services,
- determine the extent of the need for various services, the costs of providing the necessary services and the benefits which would be derived from providing these services,
- provide necessary medical and social evaluations and coordinated residential care treatment and training services to assist the handicapped individual to achieve his maximum potential for independence and personal development or to alleviate substantial impairment to normal functioning of the individual or family unit,
- use existing community services, facilities, resources and funds whenever possible. The resources of the handicapped individual and his family (i.e., income, savings, health insurance, disability benefits, workmen's compensation, etc.) were to be used before State funds were made available and
- purchase services from private physicians, allied health personnel, local government and voluntary agencies meeting standards of quality established by the Department.

Project funds were not to be used to construct new residential facilities. Institutional care was limited to care of persons so severely handicapped that other care services would be inappropriate. Home care services were to be provided whenever they could be used feasibly as an alternative to institutional care.

On the basis of this project, realistic recommendations were to be made for the provision of services necessary to enable handicapped persons to live as normal lives as possible.

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[1] Senate Bill No. 934, 1965. See Appendix A.

"Residential Care" was used in the broad sense, embracing all types of services and living arrangements appropriate for individuals who are severely handicapped and here does not denote special institutions. "Residential Care" thus would include a flexible range of housing situations and a determination of which care services are essential and appropriate for the individual handicapped person's well-being.

METHODS OF PROCEDURE

To carry out this project, a core managerial staff consisting of a health program advisor, medical social worker and clerk was established in the Bureau of Chronic Diseases, State Department of Public Health. In addition, a physician and a public health nurse consultant from the Bureau were assigned part-time to the project to provide administrative and medical direction. The physician directed the project and provided leadership to the State and local staff, consulted with State and local agencies, medical groups and other physicians to assure quality services.

Plans for the project were developed, local staff requirements determined and arrangements made for office space. A project advisory committee[1] was appointed and criteria of eligibility for clients were established. Two demonstration areas, Sacramento County and the City of Long Beach, were chosen with the assistance of the advisory committee; Sacramento because it represented an immediate metropolitan populace surrounded by a more rural area where services were not easily obtainable; Long Beach because it typified a setting where access to services was good and the range of residential situations broad. Within six months a local project staff consisting of medical social worker, public health nurse and clerk had been hired and operations were begun in Sacramento in April, 1966. Five months later a similar staff was in operation in Long Beach.

DUTIES OF STAFF

CORE STAFF

- plan and administer the program,
- develop eligibility criteria,
- recruit and supervise local staffs,
- estimate the number in need of care throughout the State,
- collect and analyze data,
- provide consultation, including medical, nursing and social work,
- provide guidance with difficult cases,
- contact government agencies on behalf of clients,
- authorize expenditures,
- stimulate community agencies and organizations, both for initial referrals and for development of appropriate services of high quality to which project clients could be referred upon discharge and
- report findings and recommendations to the Legislature.

Working with local agencies, project staff located eligible severely handicapped persons. As

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[1] Advisory Committee. See Appendix B.

LOCAL STAFF

- identify severely handicapped persons needing residential care services,
- interview potential clients to determine eligibility and willingness to participate,
- obtain background information from client, family and personal physician on previous medical, nursing, educational, social and other needs and services received,
- evaluate present situation to determine need for additional assistance and how to provide it,
- plan with the participant a solution to meet immediate and long-term needs, arrange for required services, determine their costs, evaluate benefits to client and his family,
- develop a discharge plan with client and evaluate the situation after discharge from project and
- stimulate local agencies and organizations to develop appropriate high quality services for these people.

news of the project spread, referrals were made by physicians, local health and welfare departments and other community agencies. Some handicapped persons contacted the project on their own. Participation was entirely voluntary. During the course of the project 200 handicapped persons were referred; 115 of them met the eligibility criteria established by the project and were selected (see Appendix C). They were chosen to represent the entire gamut of severe physical disabilities, the full range of ages and a variety of living situations and backgrounds in order to assure that information obtained on the range of service requirements, relative costs and feasibility of different approaches were applicable to the needs of essentially all handicapped Californians. The 85 not chosen were eliminated because they did not meet project criteria: they lived beyond the boundaries of the project areas, refused to provide necessary information or their selection would have overloaded the project with certain types of clients to the exclusion of the needed variety. Some withdrew themselves from consideration after they learned the nature of the project. The size of the case load was limited by the number for whom the staff could provide quality services and, at the same time, properly evaluate the benefits and costs of those services. Each project area maintained an active case load of about 50 persons, with new persons admitted as others were readied for discharge.

CHARACTERISTICS OF PERSONS SELECTED AS PROJECT PARTICIPANTS

Participants in the study represented a wide range of ages and handicapping conditions, Figure I. Ages were from 3 to 65, with an average age of 33. Women were slightly older, their average age being 37; men averaged 31.

Quadriplegia, paralysis of both arms and both legs, was the most common disability, afflicting 24 percent of the participants. Cerebral palsy, second most common condition, afflicted 20 percent. Other diseases much less frequent among the general population, e.g., muscular dystrophy, loomed relatively high in the study group because of their hereditary pattern or severely disabling nature. Major disabilities of the entire study population are also shown in Figure I. For description of major disabilities see Appendix D.

Figure I
PROJECT PARTICIPANTS BY AGE AND BY MAJOR DISABLING CONDITIONS
JULY, 1968

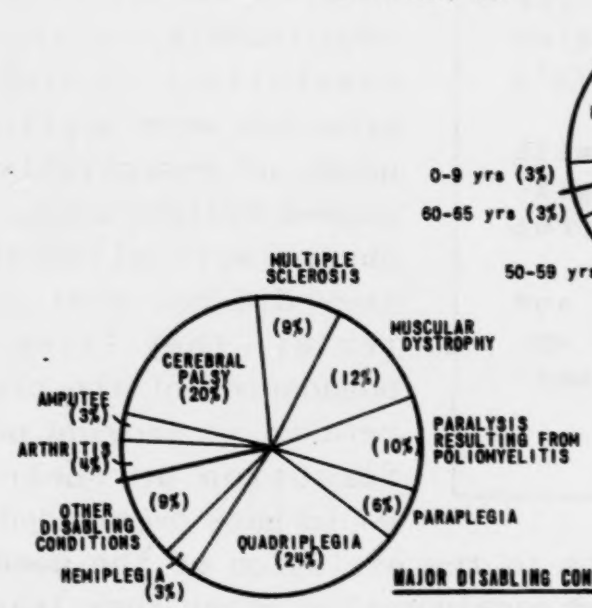


Table I

PARTICIPANTS' MAJOR DISABILITY BY AGE
JULY, 1968

MAJOR DISABILITY	AGE OF PARTICIPANT							
	Total	0-9 Years	10-19 Years	20-29 Years	30-39 Years	40-49 Years	50-59 Years	60-65 Years
Total	113	3	21	29	19	24	16	3
Arthritis	5	-	-	1	-	2	2	-
Amputee (including congenital)	3	-	1	2	-	-	-	-
Cerebral palsy	23	2	6	8	3	2	2	-
Multiple sclerosis	10	-	-	1	2	4	3	-
Muscular dystrophy	14	1	6	-	2	1	3	1
Paralysis resulting from polio	11	-	2	3	2	3	-	1
Paraplegia	7	-	1	3	1	2	-	-
Quadriplegia	28	-	3	7	8	7	3	-
Hemiplegia	4	-	-	2	-	-	1	1
Other	10	-	2	2	1	3	2	-

Note: "Other" includes: astrocytoma on cervical spinal cord; bilateral paralysis; central nervous system degeneration (3); congenital deformities; Friedreich's ataxia; Guillain-Barre syndrome; scleroderma.

Table I shows participants' major disability by age. A majority of the younger participants were afflicted by cerebral palsy or muscular dystrophy.

Males with quadriplegia and cerebral palsy accounted for six out of every ten participants. A slightly different pattern of disability was shown by the 45 women participants with multiple sclerosis being most prevalent, Table II.

Table II

PARTICIPANTS' MAJOR DISABILITY BY SEX
JULY, 1968

MAJOR DISABILITY	TOTAL		MALE		FEMALE	
	Number	Percent	Number	Percent	Number	Percent
Total	115	100	70	100	45	100
Arthritis	5	4	1	1	4	9
Amputee (including congenital)	3	3	2	3	1	2
Cerebral palsy	23	20	18	26	5	11
Multiple sclerosis	10	9	1	1	9	20
Muscular dystrophy	14	12	10	14	4	9
Paralysis resulting from polio	11	10	6	9	5	11
Paraplegia	7	6	3	4	4	9
Quadriplegia	28	24	23	33	5	11
Hemiplegia	4	3	2	3	2	5
Other	10	9	4	6	6	13

Note: "Other" includes: astrocytoma on cervical spinal cord; bilateral paralysis; central nervous system degeneration (3); congenital deformities; Friedreich's ataxia; Guillain-Barre syndrome; scleroderma.

Nearly a third of the participants were disabled as the result of an hereditary condition or congenital defect, a fourth by accidents, Table III. The proportion of any one condition in the study group is not necessarily the same as that in the general population.

Table III

PARTICIPANTS BY CAUSE OF DISABLING CONDITION
JULY, 1968

CAUSE OF DISABLING CONDITION	NUMBER	PERCENT
Total	115	100
Accidents	33	29
Automobile	13	11
Swimming	9	8
Firearm	4	3
Other	7	6
Congenital defects or perinatal causes	25	22
Degenerative diseases	18	16
Nervous system	13	11
Other systems	5	4
Hereditary defects	15	13
Infection	15	13
Unknown	9	8

Note: Percents are rounded independently and may not add to total.

All participants were permanently disabled. All for whom it had been deemed advisable had received physical rehabilitation to bring them to, or restore them to, their maximum degree of functioning. For the most part these were the people for whom rehabilitation had ceased.

In addition to, or as a part of, their primary disability, 15 participants had communication problems so severe that a stranger was unable to, or at least had great difficulty in understanding them. Ten participants had trouble seeing even when wearing glasses. Three were deaf or had serious trouble hearing even with a hearing aid.

Table IV

NUMBER OF YEARS PARTICIPANT HAS BEEN SEVERELY DISABLED BY MAJOR DISABILITY
JULY, 1968

MAJOR DISABILITY	NUMBER OF YEARS PARTICIPANT HAS BEEN SEVERELY DISABLED							
	Total	0-4 Years	5-9 Years	10-19 Years	20-29 Years	30-39 Years	40-49 Years	50-59 Years
Total	115	31	26	34	14	4	4	2
Arthritis	5	-	3	1	1	-	-	-
Amputee (including congenital)	3	-	-	1	2	-	-	-
Cerebral palsy	23	1	1	6	8	3	2	2
Multiple sclerosis	10	4	4	2	-	-	-	-
Muscular dystrophy	14	2	6	5	-	1	-	-
Paralysis resulting from polio	11	-	-	10	1	-	-	-
Paraplegia	7	4	1	2	-	-	-	-
Quadriplegia	28	14	8	5	1	-	-	-
Hemiplegia	4	2	1	1	-	-	-	-
Other	10	4	2	1	1	-	2	-

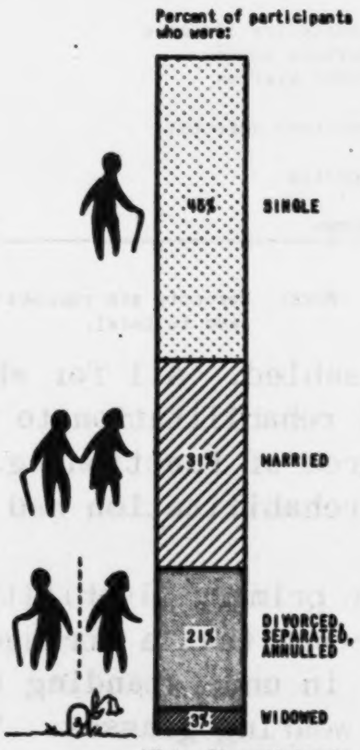
Note: "Other" includes: astrocytoma on cervical spinal cord; bilateral paralysis; central nervous system degeneration (3); congenital deformities; Friedreich's ataxia; Guillain-Barre syndrome; scleroderma.

Table IV makes it clear that the need for residential care of a severely handicapped person can develop at any time regardless of how long he has lived with his condition.

Most project participants (61 percent), like most Californians, were born outside the State. By comparison, 56 percent of Californians counted in the 1960 Census were born outside the State.[1] For the most part it was the older participants who were born out-of-state, but families of non-native-born participants had lived in their present county (Sacramento or Los Angeles) for an average of 13 years, in some cases as long as 40 years or more.

Figure II

MARITAL STATUS OF PARTICIPANTS, 20 YEARS AND OVER
JULY, 1968



Note: 91 participants were 20 years of age or older.

Racially, the participants were also comparable to the general makeup of the State's population. About 90 percent were white; 10 percent were nonwhite. In 1960, California's population was 92 percent white.[1] Thirteen percent were veterans of U.S. armed forces, all between 34 and 50 years of age. Ninety-one participants (79 percent) were 20 years of age and over; of this latter group, the majority (55 percent) were or had been married, Figure II. This is not as large a proportion as is found in the general population.

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[1] U.S. Bureau of the Census, U.S. Census of Population: 1960, General Social and Economic Characteristics, California. Final Report PC(1)-6C. U.S. Government Printing Office, Washington, D.C., 1962.

The educational attainments of the group were impressive. Of the participants 20 years and over, nine out of ten had completed high school, Table V. One-fourth were continuing their formal education; 28 were attending school; one was being tutored at home. Seven of the participants who had been disabled before 4 years of age and who were currently 20 years and over had attended college; three had graduated. None of the ones disabled after four years of age had completed less than fifth grade. One disabled during childhood had even received an advanced college degree.

Table V

HIGHEST SCHOOL GRADE COMPLETED, BY AGE WHEN SEVERELY DISABLED AND PRESENT AGE JULY, 1968

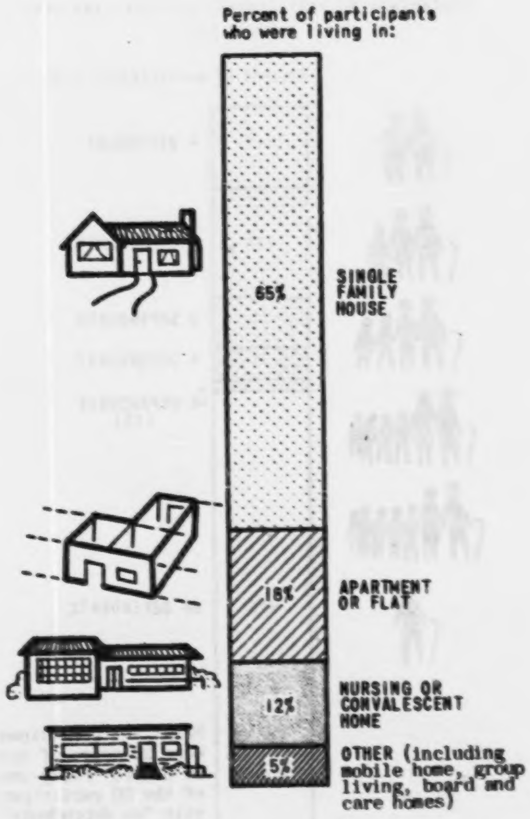
HIGHEST SCHOOL GRADE COMPLETED	TOTAL	DISABLED AT 4 YEARS AND UNDER		DISABLED AT 5-19 YEARS		DISABLED AT 20 YEARS AND OVER
		Present Age		Present Age		
		Less than 20 Years	20 Years and Over	Less than 20 Years	20 Years and Over	
Total	115	14	21	10	14	56
No Formal Schooling	4	2	2	-	-	-
Fifth Grade or Lower	5	3	2	-	-	-
Sixth Through 11th Grade	23	2	3	8	2	8
12th Grade	45	2	5	2	6	30
Attended College, but Did Not Complete	19	-	4	-	3	12
Completed (4-year) College	6	-	3	-	2	1
Advanced College Degree	3	-	-	-	1	2
Attended Only Ungraded Schools	6	4	2	-	-	-
Unknown or Unspecified	4	1	-	-	-	3

Four of every five participants lived in a private household as distinguished from an institution or group living arrangement. This may partially reflect the method of case referral. Thirty-seven percent lived in their parents' household. Another 37 percent lived in their own household either as head of household (27 percent) or as a spouse (10 percent), Figure III. The 20 percent who did not live at home lived in nursing or convalescent homes (15 people), group living situations (4 people), board and care homes (3 people) or hospitals (1 person).

Figure III

WHERE PROJECT PARTICIPANTS LIVE

JULY, 1968



The 31 participants (27 percent) who were heads of households lived as follows:

- 16 with more than one relative
  - 7 with spouse and children
  - 6 with children only
  - 3 with children, other relatives and/or attendants

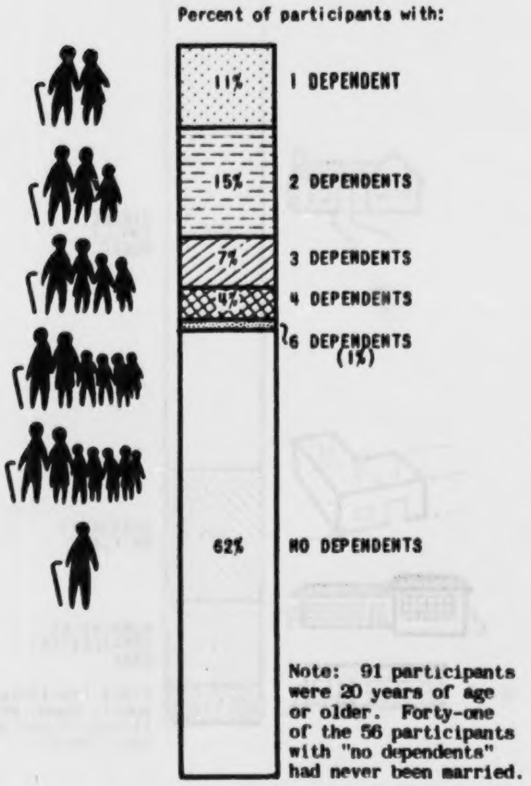
- 2 with spouse only

- 10 with other persons
  - 7 with friends and/or attendants only
  - 3 with other combinations of relatives and attendants

- 3 alone, with attendants or others giving part-time help

The 43 participants (37 percent) who lived in their parents' homes were, on the average, 22 years old. The spread in age was considerable, however, 3 to 54 years. Parents ranged in age from the 24-year-old parents of the project's youngest participant to a 78-year-old widow. Thirty-one of the 43 who lived in their parents' homes lived with both parents. Twelve lived with a widowed, separated or divorced mother.

Figure IV
DEPENDENTS OF PARTICIPANTS 20 YEARS AND OVER
JULY, 1968



Note: 91 participants were 20 years of age or older. Forty-one of the 56 participants with "no dependents" had never been married.

Among the 91 participants 20 years and over, 35 had from one to six dependents, a total of 78 dependents. Most of the 35 participants (74 percent) lived with their dependents and the majority of the 35 received some public assistance, Figure IV.

METHODS OF OPERATION

The staff worked in three ways to carry out the project. These were:

1. *To Determine the Number of Severely Physically Handicapped of Normal Mentality in California.*

To determine the extent of the need for residential care services, an estimate of the number of severely physically handicapped persons of normal mentality in California was necessary. Of the many prevalence studies of various specific disabilities made in different parts of the nation, none dealt with a group of individuals comparable to those delineated as physically handicapped and mentally normal by the California Legislature. It was therefore necessary to develop this information as accurately and as economically as possible within the limits of the total project budget.

Two basic ways to develop such data were open: 1) to count each individual known to be severely handicapped as defined in a given area of known population and from the count make a projection to the total population of the State; or 2) to survey a sample of the total State population and on the basis of the proportion of severely handicapped persons to others in this sample, estimate their proportion of the total population. Since both methods have advantages and disadvantages, the decision was to use both.

For the first, Sacramento County was selected as the sample area because it has a relatively small total population; it is the medical as well as the economic and social center of the surrounding area; it has active public and voluntary health and social service programs and the general characteristics of the population - age, race, income, employment, education, family composition - are comparable to the State averages.

For the second method, a random sampling of the entire State population, a minimum of 2,000 households, was planned. Arrangements were made to do this survey jointly with the Department of Rehabilitation which needed even more extensive information on the handicapped. The study was to use the methodology of a six-state rehabilitation survey currently in progress elsewhere and was to be funded through the Department of Rehabilitation. After ten months of negotiation and preparation the Director of the State Department of Public Health was informed by the Department of Rehabilitation in October, 1968, that it could not go through with the plan. At that late date, any such survey had to be abandoned for one could not be completed in the time remaining to the project.

The Sacramento Registry

The count or registry was designed to include all severely handicapped persons under 65 years of age known to be living in Sacramento County on a given day, July 1, 1966. Information was obtained on a confidential basis from those agencies known to be in contact with or which provided some service to the handicapped. Approximately 100 agencies, including the major health, welfare and voluntary service agencies, cooperated by making their files available in confidence to the project staff. Additional information was obtained from the public schools, physicians and from nursing and boarding homes in the area, and all other known sources through which handicapped persons could be located.

Individual cards were prepared for each Sacramento resident who met the specified criteria of "severely physically handicapped, mentally normal". Duplicate counting was avoided by matching names and birthdates. There undoubtedly was underreporting because some handicapped persons were not known to any of the agencies; on the other hand, because some agency records were incomplete or not up to date, the count probably includes some persons who were not severely handicapped, were not mentally normal or who were not living in Sacramento on July 1, 1966. The two probably offset each other.

"Severely physically handicapped" was defined as an individual with one or more severe, permanent handicaps that can be verified medically and that cannot be substantially eliminated through generally accepted medical procedures, whose primary handicap is other than blindness, deafness or tuberculosis, who is so handicapped by his disabilities as to be dependent upon others for his daily care and well-being and who is in reasonably good health to the extent that he does not require long-term hospitalization. "Mentally normal" was defined as including persons who are not retarded or mentally ill to the extent that they qualify for the institutional care services of the California Department of Mental Hygiene.

After reviewing several thousand agency records, registry cards were prepared for approximately 4,000 handicapped persons; of this number, 302 were considered to be severely physically handicapped, mentally normal and in need of residential care services. Only about one-third were under 20 years of age, Table VI.

Table VI

REGISTRANTS BY AGE
SACRAMENTO COUNTY

AGE	REGISTRANTS Number	 Percent
Total	302	100
Less than 10 years	40	13
10-19 years	68	23
20-29 years	31	10
30-39 years	37	12
40-49 years	43	14
50-59 years	52	17
60-64 years	27	9
Exact age not specified	4	1

Note: Percents are rounded independently and may not add to total.

Cerebral palsy was by far the most common disability, representing nearly one-third of the 302 registrants. The relative frequency of the disabling conditions among those included in the registry is shown in Table VII.

Table VII

REGISTRANTS BY DISABLING CONDITION
SACRAMENTO COUNTY

DISABLING CONDITION	REGISTRANTS Number	 Percent
Total	302	100
Arthritis	37	12
Cerebral palsy	97	32
Hemiplegia	8	3
Multiple sclerosis	39	13
Muscular dystrophy	28	9
Paraplegia	14	5
Paralysis resulting from polio	16	5
Quadriplegia	30	10
Other	33	11

Projections based on the Sacramento County data, when adjusted for the population increase of the past two years, indicate that in California in July, 1968, there were approximately 9,600 severely physically handicapped persons of normal mentality in need of residential care services. This estimate may be off by as much as 10 percent in either direction because of the subjective decisions made as to whether a particular individual came within the survey definition. A 10 percent variation would yield a range of 8,600 to 10,600.

Based on the registry figure for Sacramento County, an estimated number of severely handicapped persons, mentally normal, was made for each county, Figure V.

Data From Other Sources

Data from certain earlier surveys made in California and a national survey were studied to check the validity of the estimates based on the Sacramento registry.

In 1954-1955 a statewide survey was conducted to obtain information related to illness. As a part of this survey, persons with chronic conditions or disabilities were asked to consider how they believed the condition to limit their activities. The following numbers fell into the most limited class: 2 out of every 1,000 children under 15 years of age (so classified by their parents), 1 out of every 1,000 persons 15-44 years of age and 6 out of every 1,000 persons 45-64 years of age.[1]

In a similar statewide survey, conducted in 1958, people were questioned concerning limitations of mobility. Into the category indicating greatest degree of limitations fell: less than 1 out of every 1,000 children under 15 years of age, about 1 out of every 1,000 persons 15-44 years of age and 6 out of every 1,000 persons 45-64 years of age.[2] Similar questions to those on the 1958 California Health Survey were asked on a National Health Survey, covering a four-year period from July 1957 to June 1961. The national data show that in this most severe limitation group there were approximately 9 per 10,000 children under 15 years of age, 14 per 10,000 persons in the 15-44 age group and 67 per 10,000 in the 45-64 age group.[3]

Since the State and national figures were in such close agreement it seemed appropriate to apply the national rates to California's 1968 population, Table VIII.

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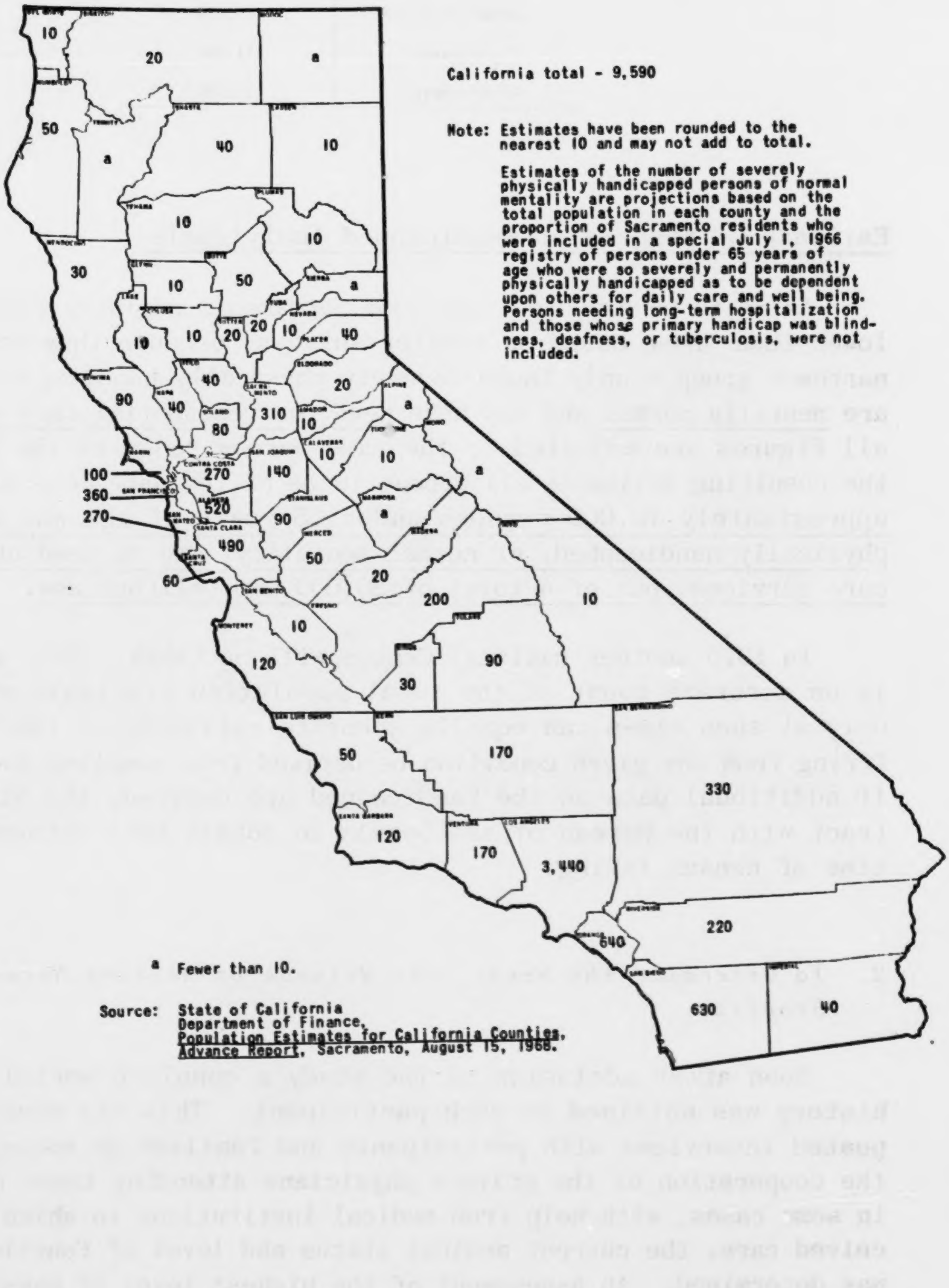
[1] State of California, Department of Public Health, Health in California, p. 90.

[2] State of California, Department of Public Health, The California Health Survey, 1958, p. 37.

[3] U.S. Department of Health, Education, and Welfare, Public Health Service, National Health Survey, Bed Disability Among the Chronically Limited, United States, July 1957-June 1961, Series 10, No. 12, Washington, D.C., U.S. Government Printing Office, 1964, p. 16.

Figure V

ESTIMATED NUMBER OF
SEVERELY PHYSICALLY HANDICAPPED PERSONS OF NORMAL MENTALITY
CALIFORNIA COUNTIES, 1968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520
90
a
490
50
60
20
200
10
10
120
90
30
50
170
330
120
170
3,440
220
640
630
40

California total - 9,590

Note: Estimates have been rounded to the nearest 10 and may not add to total.

Estimates of the number of severely physically handicapped persons of normal mentality are projections based on the total population in each county and the proportion of Sacramento residents who were included in a special July 1, 1966 registry of persons under 65 years of age who were so severely and permanently physically handicapped as to be dependent upon others for daily care and well being. Persons needing long-term hospitalization and those whose primary handicap was blindness, deafness, or tuberculosis, were not included.

[a] Fewer than 10.

Source: State of California
Department of Finance,
Population Estimates for California Counties, Advance Report, Sacramento, August 15, 1968.

Table VIII

ESTIMATED NUMBER
OF HANDICAPPED PERSONS
BY AGE
CALIFORNIA, 1968

AGE	HANDICAPPED PERSONS
Total	43,000
Under 15 years	5,000
15-44 years	11,000
45-64 years	27,000

Estimate of Numbers of Handicapped Individuals

As is to be expected, the 1968 Sacramento registry figures are much lower than those based on earlier surveys, because they include a much narrower group - only those severely physically handicapped persons who are mentally normal and who have need for residential care services. If all figures are adjusted to the same narrow range of the handicapped, the resulting estimates all appear to be of the same general magnitude - approximately 10,000 persons under 65 years of age who are severely physically handicapped, of normal mentality, and in need of residential care services, out of a total of 20,000,000 Californians.

In 1970 another national Census will be taken. Only at such times is an accurate count of the total population available and therefore only at such times can equally accurate estimates of the numbers suffering from any given condition be derived from sampling the population. If additional data on the handicapped are desired, the State can contract with the Bureau of the Census to obtain this information at the time of census taking.

2. *To Determine the Needs, the Methods of Meeting Needs, Costs and Benefits.*

Soon after admission to the study a complete social and medical history was obtained on each participant. This was done through repeated interviews with participants and families or associates. With the cooperation of the private physicians attending these patients and, in some cases, with help from medical institutions in which they had received care, the current medical status and level of functioning of each was determined. An assessment of the highest level of physical and mental functioning attainable by the participants was made. The immediate and urgent needs which resulted from the acute situation which brought the client to the project were taken care of first. The additional care required to bring the participant up to his maximum potential for self-care and to meet his long-range needs was then assessed.

Once needs were determined, project staff attempted to fulfill them through existing community resources and facilities. Only when the services of the resources and facilities were unavailable, inadequate or of insufficient quality were project funds used to purchase services or supply needs. All participants were followed closely to assess the effect - the benefits, if any - of the additional care or services. In this way, cost could be weighed against benefit. Problems encountered by clients and families in the course of daily activities could be detected. The variety of ways individuals or families had found on their own to meet their needs satisfactorily could be observed.

Project nurses and social workers made an average of 35 contacts per participant, more than 2 contacts each month. This includes initial case finding, evaluations and reevaluations, continuing contacts for counseling, planning and support and contacts with other agencies and organizations on behalf of the individual participant. It does not include consultation sessions with Bureau of Chronic Diseases staff nor the visits made to follow the course of participants after discharge from the project. The subject matter of these contacts covered the full range of the participants' needs. Of necessity, services were broader than "food, shelter and clothing". For the numbers of participants shown in Table IX, project staff either provided the services indicated directly, purchased them, helped the individual obtain them or, in a few instances, sought a particular service for a participant but was unable to obtain it at all. It is obvious that evaluation and counseling services - case management - were the most frequently needed services.

Table IX

SERVICES TO PROJECT PARTICIPANTS
JULY, 1968

SERVICE	TOTAL	NUMBER OF PARTICIPANTS FOR WHOM SERVICE WAS Provided Directly	Purchased from Vendor	Obtained from Another Agency	Obtained by Participant with Project Assistance	Sought, but Could Not Be Obtained	Combination of the Preceding	Other
Evaluations								
Medical (physician)	14	-	3	6	5	-	-	-
Nursing	114	114	-	-	-	-	-	-
Social work	106	106	-	-	-	-	-	-
Psychological	6	-	-	6	-	-	-	-
Physical therapy, occupational therapy or speech therapy	5	-	-	3	1	1	-	-
Welfare	8	-	-	-	8	-	-	-
Other evaluations	22	1	1	12	7	1	-	-
Care Services								
Medical care	31	-	3	6	13	9	-	-
Nursing care	32	8	4	5	4	11	-	-
Dental care	10	-	4	3	-	3	-	-
Counseling								
Nursing counseling	100	100	-	-	-	-	-	-
Social work counseling	89	88	-	1	-	-	-	-
Other Services								
Educational services	30	2	6	-	8	14	-	-
Housing services	33	9	3	11	3	7	-	-
Attendant care	35	3	13	4	5	10	-	-
Housekeeper/homemaker	24	-	6	2	3	13	-	-
Advocacy	17	7	-	1	-	6	-	3
Drugs	23	4	9	1	4	3	2	-
Medical supplies or equipment	47	2	9	17	8	6	4	1
Transportation	46	24	10	-	4	4	3	1
Recreation	56	10	15	1	11	13	5	1
Household furniture and appliances	19	4	12	-	1	2	-	-
Miscellaneous services	47	15	5	6	7	8	-	6

Each participant, when taken into the study, was informed that project services could not last beyond the latter part of 1968, by which time he would be referred to an appropriate community agency for his continuing needs. Each was expected to participate in shaping his own discharge plan.

Direct expenditures were kept at a minimum by making full use of all other resources that could provide the needed services or supplies. In half of the cases it was not necessary to make any direct expenditure. In the other cases, the amount spent ranged from a low of $3 to over $3,000. Direct expenditures averaged $267 or $16 per person per month of project participation. Ten cases accounted for 57 percent of all direct expenditures. Other project expenses, salaries, et cetera, brought the average total yearly cost per participant to approximately $1,000. This does not represent the total cost of the additional care given during the project, for the staff made full use of any other resources that could provide needed services or supplies. Considerable staff time was devoted to each participant and, as a result, staff salaries were the largest portion of indirect expenses.

3. *To Study the Variety of Methods of Furnishing Residential Care.*

Although those who were to undergo intensive study in the project were limited to 115, an additional 100 handicapped persons were examined more superficially to gain broader experience and to assess a greater variety of ways of furnishing residential care. Also, the new residential facility developed by the Spastic Children's Foundation of Los Angeles, an adult program of institutional care, was studied (see Appendix E - Special Studies on Housing).

FINDINGS

GENERAL

The vast majority of severely handicapped persons in California live at home and are provided for by their families. The project case load was heavily weighted towards those who needed urgent help; however, even those individuals and families who did not need financial assistance were found to need professional guidance in pinpointing their needs, obtaining necessary services and in planning for the future.

The handicapped persons studied in depth were a heterogeneous group as to degree of disability, socioeconomic status, level of education, ability to cope with problems stemming from their disabilities and in many other respects; yet certain common threads bound the group together. For them the simple process of daily existence is an effort which literally cannot be accomplished without help from others. This dependence on others, and often on a machine as well, engenders an ever-present sense of fear. Each is forced by his physical disability to struggle to perform some of the simplest tasks of daily living - breathing, eating, moving, speaking - which most of us do without thought. Each suspects a reduced life expectancy, harbors a fear of impending disaster and lives under constant shadow of a medical emergency. The simple cold, a minor bladder infection - usually no problem to the physically normal - may rapidly create a medical crisis for the handicapped. Each has an alert, active mind, normal ambitions and normal desires for mental stimulation, occupation, recreation and community life. Each hopes to live with dignity and with some degree of independence. Each has had to learn to adjust to his handicap. Together with his family, each lives in fear of the future - that day when his family is no longer there or no longer able to take care of him and there is no one to turn to.

Each project participant needed some care or basic service he was not receiving. These needs, encompassing residential, medical, social, educational, vocational, psychological and other fields, often led to very complex situations for the participant as an individual or for the family as a unit. When more than one member of the family was handicapped, problems were compounded. If the breadwinner was disabled, family stability was often in jeopardy. Life was a series of crises with an ever-present sense of impending calamity. Few families had the psychological strength to be able to meet repeated insults with equanimity and alone. The majority, however, could meet them with surprisingly little outside support.

Some participants needed certain residential care services because their families lacked financial resources to purchase them. Others, unaware of available services, needed guidance to obtain appropriate service from public or private agencies. Some being cared for at home were vulnerable because their parents were aging and becoming less able to care for them. Others, unaware of their potential for improvement, simply "existed".

To satisfy his needs or to find other solutions to offset them, the handicapped person or his family had to seek out information, resources and services on their own. Thus, an undue burden was placed on someone already seriously handicapped. Many had given up. When the project staff took on such problems, it found that their solution required the coordinated efforts of a planning team and often many different health and social agencies. In this project each local staff served as the planning team.

Among participants as a whole, staff found the potential for achieving some degree of improved functioning good. Some needed only instruction and a slight push to be able to go after and secure their own help; others were incapable of independent functioning. The one most needed and most universally beneficial service the project had to offer was case management, i.e., counseling, both medical and social. To know that someone had concern for them and that there was some outside person to whom they could turn was all some of them needed to start them on a better course.

PHYSICAL LIMITATIONS

All participants were severely limited in ability to perform ordinary tasks of daily living, particularly tasks requiring considerable physical effort or good muscular control. Communication was the least difficult - 86 percent could accomplish this by themselves. Many - 47 percent - needed help with eating; 73 percent needed help to dress or undress. Nearly three out of four had to be helped with toileting. Nine out of ten needed help to perform simple housekeeping tasks. Half the participants could move about by themselves within their homes; only 20 percent could move about outside their homes without help, Table X.

Table X

ABILITY TO PERFORM ACTIVITIES OF DAILY LIVING
JULY, 1968

ACTIVITY	Total	PERCENT OF PARTICIPANTS WHO				
		Had No Serious Problem	Had Some Difficulty	Require Some Help	Require Help	Other
Mobility within the home	100	9	43	21	27	1
Mobility outside the home	100	4	16	31	48	1
Communication	100	76	10	8	6	1
Housekeeping	100	2	9	18	70	1
Eating	100	34	19	24	23	1
Dressing	100	7	19	20	53	1
Toileting	100	10	15	19	55	1

Note: Percents are rounded independently and may not add to total.

An individual becomes burdensome when he is unable to accomplish any one of these activities, but when he must have help to accomplish a number of basic tasks, the provision of care becomes constant and exhaustive. Most participants, when given proper care and training, were eventually able to perform at least certain activities of daily living with partial help, or in some instances, without much help. These latter, together with those participants whose physical abilities improved substantially during the course of the project, make up the 22 percent listed in Table XI who were not totally dependent upon others for any activity of daily living at the close of the project.

Table XI

NUMBER OF SPECIFIED ACTIVITIES WITH WHICH PARTICIPANTS MUST HAVE (ALMOST) COMPLETE HELP

SPECIFIED ACTIVITY	PERCENT OF PARTICIPANTS
All seven	4
Six	12
Five	11
Four	12
Three	15
Two	13
One	11
None	22

Most participants were able to perform some additional basic tasks without help. Eighty-two percent were physically able to read a book or magazine and turn the pages by themselves. Seventy-four percent were able to type or write; 82 percent could use a regular or special telephone without help. However, only 9 percent could walk 50 yards on a level surface unaided. Sixty percent could not propel a manual wheelchair over the same distance.

All participants needed and used some special devices or equipment. Nearly all, 84 percent, used wheelchairs; 10 percent used electric wheelchairs. The proportion of participants who used various assistive devices are shown in Figure VI.

Figure VI

ASSISTIVE DEVICES REGULARLY USED BY PARTICIPANTS JULY, 1968

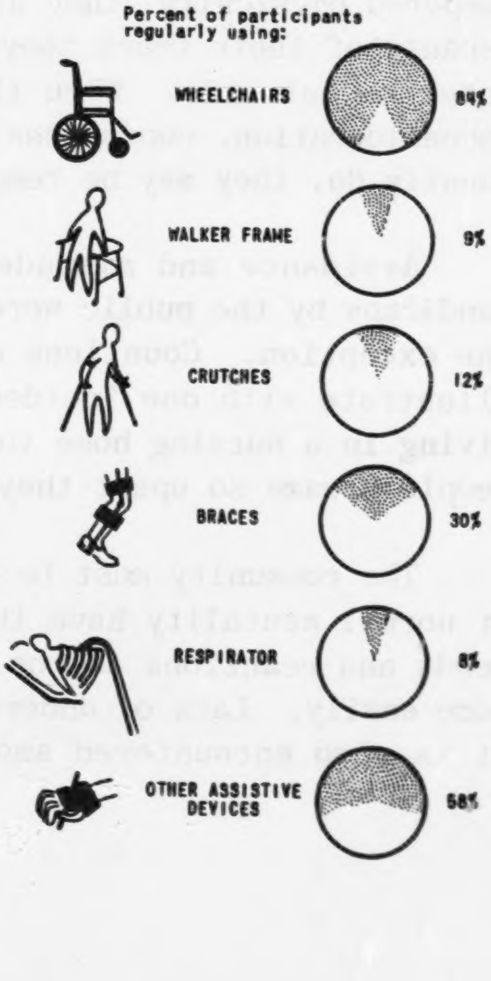


Table XII

PARTICIPANTS LIVING AT HOME
BY SOURCE OF HELP

SOURCE OF HELP	PARTICIPANTS
Total Living at Home	92
Help from family members	47
Live-in attendants	12
Help from outside source	33
Attendant	16
Housekeeper or domestic	7
Neighbor or friend	5
Relative	3
VNA plus domestic	1
Home Health Aide	1

Project participants received assistance with daily living from a variety of sources. The 92 who lived in a private household received most of their help from relatives living in the same household. Twelve participants had live-in attendants; thirty-three received help regularly from an outside source, Table XII.

COMMUNITY ATTITUDES

Modern practice of rehabilitation has brought the vast majority of the severely handicapped to a point where they can live in and, hopefully, contribute to the community, thus lessening their drain on society. Communities have an obligation to include them in their activities and to permit them to contribute their individual skills and abilities. A great need for increased community awareness and recognition of the existence and potential of its handicapped members rapidly became apparent to the project staff. A charitable society daily can pass by entire groups but not see them as people, while at the same time it is generously supporting them.

Entrance of handicapped persons into community life is not easy. Hampered physically, they are frequently required to develop new skills. Because of their fears they need emotional support and encouragement to enter normal life. When they encounter confusion, pity or revulsion, inconsideration, condescension or lack of understanding, as they so frequently do, they may be tempted to withdraw.

Avoidance and misunderstanding of persons with severe physical handicaps by the public were familiar reactions seen in the project, not the exception. Countless examples could be cited. Let it suffice to illustrate with one incident. When several young handicapped persons living in a nursing home took a "stroll" in their electric wheelchairs, people became so upset they called the police.

The community must be made aware that severely handicapped persons of normal mentality have the same intellectual abilities and emotional needs and reactions as the physically normal. Such awareness does not come easily. Lack of understanding is not limited to the lay community; it is also encountered among professionals. Some professionals were apprehensive about working with severely handicapped persons and attempted to avoid accepting them for services since they expected little improvement in function and, hence, felt their efforts would be wasted. Even staffing the project was not easy because of such attitudes. This same reluctance to serve handicapped persons was also found among some representatives of public agencies. In one instance a public housing authority refused to allow necessary and permissible alterations, including the installation of ramps, in order to make living quarters more suitable for handicapped persons. One public agency is "known" to the handicapped for discouraging potential clients when they make phone inquiries about services. Frequently, project staff was asked to intervene on behalf of clients to speed up services trapped in "red tape", to induce public agencies to reexamine regulations for the purpose of achieving the full intent of the law and to urge review of service requests which had not been understood. Professional - for that matter nonprofessional - staff who render services to the severely handicapped must realize how traumatic a negative or indifferent attitude can be to these clients.

COMMUNITY RESOURCES

The project found numerous community resources available to the handicapped, many unused. Some agencies were unknown to the handicapped and made no effort to reach out to them. Some offered a service in a form unusable to the handicapped or his family. Voluntary agencies carry a large responsibility for bringing help and diversion to the handicapped, but their resources are limited. The majority of agencies offer but a single service. Some services went unutilized because agency personnel tended to assess clients only in terms of the service offered by that agency and the one service alone would not have helped. Few professional workers in agencies assumed responsibility to coordinate services from other sources or even to refer handicapped persons to other agencies for additional needed services. Frequently, the severity of the individual's handicaps frightened the unprepared professional who then was unable to offer adequate counseling and assistnace. Sometimes agency professional staff had too little knowledge of services needed by the client to offer a satisfactory level of counseling. At other times professionally qualified staff were not assigned to the severely handicapped because working with them was considered unrewarding. Project staff found that only the highly trained and the highly skilled could unravel the complex problems posed by some of the severely handicapped. When a perseverant client encountered a well motivated, skilled agency worker who took time to evaluate and give heed to his needs, more effective services were forthcoming.

Many project participants recounted stories of undue difficulties encountered, for whatever the reason, in obtaining services. For example, in one distressing case, a mother's application for public assistance was mishandled for several years, costing her infinite anguish and considerable sums of money for private care which she could ill afford.

It can be very serious when a handicapped person, after being confronted with ignorance, indifference or insensitivity turns away from public or voluntary agencies and stops seeking help. For some project participants it had resulted in delayed care or no care for both acute and chronic conditions, a costly neglect.

Project staff worked with agency personnel to give them an understanding of the special problems of the severely handicapped, but mentally normal. When they did, agency personnel worked more effectively with the handicapped, but too often the worker, so stimulated, then found himself frustrated by rigid agency policies or lack of funds.

A significant problem for severely handicapped participants was to find out which community agency could meet particular needs and then to persevere in obtaining its help. Many of them had come to rely on only one agency - usually public assistance (ATD) or vocational rehabilitation (VRS) - even though that agency left many of their needs unsatisfied.

The one community agency most often utilized was the Welfare Department. Fifty-six percent of the participants were receiving financial assistance under the ATD program; 37 percent had received vocational training or counseling from Vocational Rehabilitation Service. Crippled Children Services served 11 of the 26 participants who were under 21 years of age.

INADEQUACIES OF EXISTING PROGRAMS

The two programs upon which handicapped persons are primarily dependent are health and welfare, but these provide for only a portion of their total care needs. There is no one program to which they can turn to satisfy all their needs nor is there a unifying program that can bring all the separate pieces together. The benefits of coordinated services can best be illustrated by an example.

One participant who had been injured in an auto accident was initially treated as a quadriplegic in a community hospital, transferred to a medical rehabilitation center and finally sent home to be cared for by his family. He and his dependents were being supported by public welfare funds. Little effort had been made to encourage him to find a way to support himself and his family. His wife had not been shown how to care for him and there was no follow-up by any responsible agency to see that he received proper care. As a result, he deteriorated to the point that he lost much of the benefit of rehabilitation and required further expensive hospitalization.

After he returned home he became known to the project. Project staff, able to deal with his entire situation rather than just fragments of it, instructed him and his wife in techniques of his total health care and also taught the wife how to handle her increased responsibilities as a housewife and mother. Furthermore, they encouraged the husband to seek vocational rehabilitation despite his severe disabilities. This he did with considerable success. He has now opened a business utilizing his vocational rehabilitation training. As a result of the project's case management role and freedom to deal unrestrictedly with all aspects, the husband's present and future physical care are likely to be better and less costly to the community. There are also excellent prospects for this family to be financially independent, contributing to society rather than continuing as welfare recipients.

In this situation the Handicapped Persons Pilot Project invested a considerable amount of staff time and spent nearly $1,100, mainly for attendant care, medical equipment not available through Medi-Cal and to help the family maintain their home. At the urging of project staff the Vocational Rehabilitation Service also invested staff time and funds. Yet these combined expenditures are less costly than one hospitalization for the treatment of bedsores. If the husband's efforts are successful and the family does get off the welfare rolls there will be further, substantial savings.

The economics in this example are fairly obvious. The family was getting over $7,000 a year in welfare and disability payments. The father, in his early forties, though remaining severely disabled, could reasonably expect to live another 10 or 20 years. Payments during that period alone would be between $70,000 and $140,000; there would also be the additional treatment and hospitalization expenses resulting from inadequate care at home. The alternative, institutional care for the father, would be even more costly, particularly if the wife and two children continued on public welfare.

The following general comments about the shortcomings of particular programs can be made:

1. Medi-Cal. This Program provides for many health care needs, but is often unable to provide certain drugs or equipment needed by the severely handicapped. For example, electric wheelchairs, if authorized, would permit a wider range of mobility and a greater opportunity for education, employment and recreation. Some drugs, such as Valium, have proved especially effective in relieving severe muscle spasms, but are not available through Medi-Cal. The available substitute drugs are not as effective. Evaluation visits by home care agencies are not a covered service, even though an occasional evaluation might eliminate many therapeutic treatments.

2. Health Departments. Local health departments generally have accepted a role in the continuing medical supervision of the care of the handicapped child under the Crippled Children Services Program; however, this program can only serve children under 21 years of age. Continuing care or reevaluation of service needs cannot be provided after that age. Local health departments have been unwilling to assume a similar role for adult handicapped persons because their funds have been so limited that their efforts have been inconsequential.

3. Home Care Programs. Home health agencies could handle many of the care needs of the severely physically handicapped - in fact, essentially all of their ongoing medical and paramedical needs. Their service to project participants, however, had been very limited. They, too, did not always have the necessary qualified staff, the commitment to care for the severely handicapped nor funds to provide the care needed. Because of agency liability, these agencies could not teach health care techniques to attendants who were not in their employ and under their supervision, nor would they teach attendants or family members how to use assistive devices such as lifts. Some home care agencies do not allow their nurses to catheterize male patients. As a consequence someone not trained in the proper techniques nor in the potential dangers of catheterizing was, of necessity, given the responsibility.

Over the past three years a number of home health agencies have broadened their capabilities to handle seriously ill and disabled patients. Others are in the process of increasing their services, but many still have a limited range of services, do not offer 24-hour, 7-day a week coverage and avoid serving seriously ill or disabled patients. In the two pilot areas project staff worked with local home care agencies to increase their skills in caring for the severely handicapped. Most of the participants who have been terminated by the project were transferred to these agencies. Coordinated home care programs with their professional teams are logical home health agencies to assume the case management of the severely handicapped, once agency staffs have been trained.

> "A coordinated home care program is one that is centrally administered and that, through coordinated planning, evaluation and follow-up procedures, provides for physician-directed medical, nursing, social and related services to selected patients at home" -
>
> **Principles of Administration of Hospital-based Coordinated Home Care Programs - American Hospital Association, 1961.**

4. Vendors. Some companies rent or sell medical equipment, deliver it to the patient and teach its use, but they are not allowed to handle a handicapped individual for a proper demonstration. The attendant or family member charged with operating the lift, for example, and the handicapped person dependent upon it may, as a result, be afraid to use it. The equipment remains unused and the problem it was meant to solve remains unsolved. To avoid this, better coordination of service between vendors and health personnel is needed. Most people do not learn to use unfamiliar equipment by vision alone or by the spoken word; they need realistic demonstrations and practice before they become familiar enough with it to risk helping the severely handicapped.

5. Assistance Programs. Persons who are not financially needy are ineligible for public assistance. Such people may need various types of services, particularly counseling, but unless these individuals or their families are unusually persistent, they may not be able to obtain help. Ironically, often paying clients cannot purchase or obtain in any way services that are offered free to the indigent.

ATD allowances are found inadequate to meet the living expenses of severely physically handicapped persons. Monthly allowances in effect in July, 1968 for a severely disabled person living alone were:

Food	$ 35.00
Clothing	9.50
Transportation	6.00
Household operation	4.00
Telephone service	2.00
Personal incidental needs	8.00
Recreation and education	6.00
Services related to disability	9.00
"Cost of Living" increase	8.00
Housing and utilities as paid (maximum)	63.00
Added living expenses incidental to living alone	5.00
TOTAL	$155.50

Furniture, refrigerators, washers, sewing machines - all essential items for a family - cannot be bought on a welfare allowance. A recipient who wishes to live with a group of other handicapped persons faces a reduction in his financial assistance (an ATD regulation) which may then make group living impossible. Thus, severely handicapped welfare clients are discouraged from group living.

Allowances of $15 a month for the personal needs of handicapped persons living in nursing homes were inadequate to cover the costs of clothing, laundry, shampoos, reading material, toothpaste and other personal items. Yet, most of these people are not bedridden but must be up and dressed every day. They hope to look nice and appear well groomed. Attendant allowances, equally inadequate, are discussed elsewhere in this report. Transportation allowances do not cover the needs of these handicapped persons.

All public programs must, of necessity, operate in accordance with regulations developed to benefit the greatest number, but this results in some not getting the care or services intended. Flexibility in application or exceptions for special groups should be written into such regulations. The conditions of life for the severely handicapped of normal mentality distinguish them from every other group as to care and service needs. This difference should be taken into account.

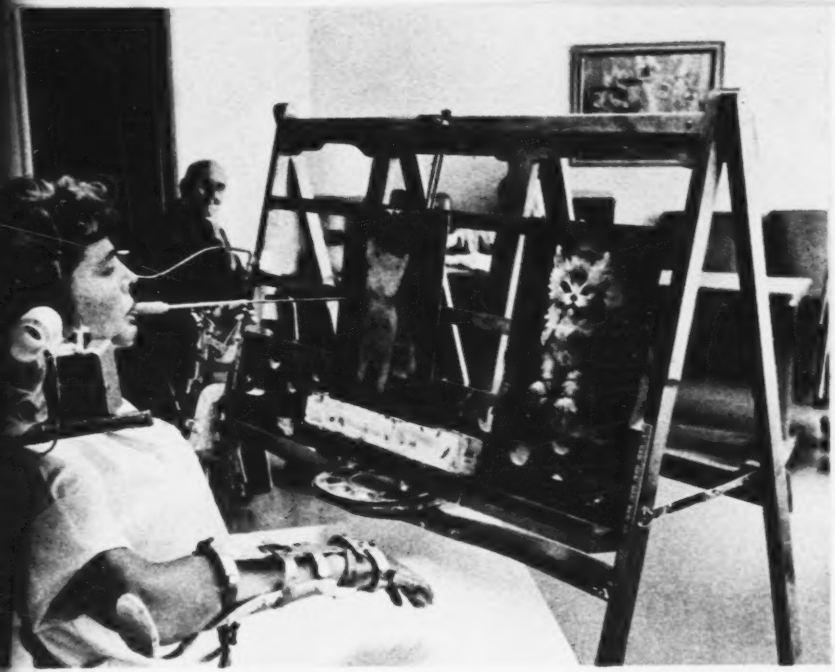
Contributions made by public assistance to the support of project participants are shown in Table XIII. Of the 92 having some source of income, 65 received aid from ATD; for 38 it was the only source of income. Twenty-three reported no income including 19 who were under 18 years of age. It should be emphasized that this may give a biased picture of the handicapped since to be admitted to the project, a participant was likely to be from a low income group.

Table XIII

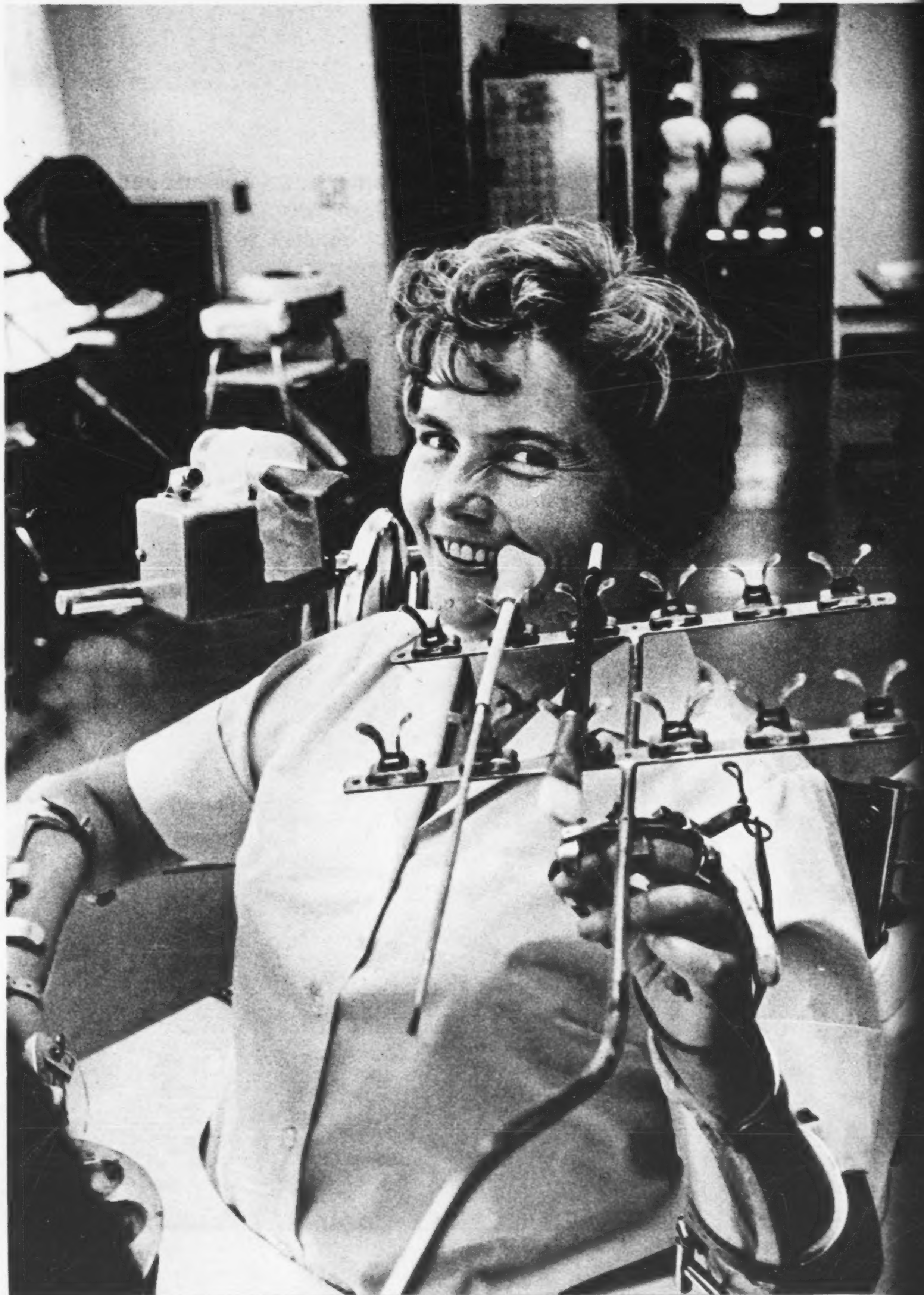
SOURCES OF INCOME OF CLIENTS
JULY, 1968[a]

TYPE OF INCOME	TOTAL	NUMBER OF CLIENTS WITH			
		No Income of the This Type	Single Source of Income	Multiple Sources of Income	Other
Total	115				
With No Income	23[b]				
With Income	92				
Wages or Salary	92	86	4	2	-
Compensation or Disability Insurance	92	85	-	7	-
Social Security	92	64	4	24	-
Veterans' Administration	92	79	2	11	-
Vocational Rehabilitation	92	92	-	-	-
ATD	92	27	38	27	-
Other Welfare	92	85	-	7	-
Other Income	92	76	1	10	5

[a] Or at time of termination of service.
[b] 19 were under 18 years of age.



A few young adults, paralyzed by polio over ten years ago, have been living in a nursing home amidst the sick and elderly. One woman, with a little help and encouragement, is now able to paint by holding a brush in her mouth, to use a special telephone, and to make an occasional trip outside the nursing home.



TOP: With the help of an attendant, a husband and wife, both severely handicapped, are able to live together in their own apartment. BOTTOM: A father, disabled by muscular dystrophy, maintains a home for his two teen-age children, and for their pet dog.

CASE HISTORIES

The following case histories serve to highlight the types of problems faced by the severely handicapped of normal mentality and their families, and to illustrate why they need help not now available. In most instances, a critical situation precipitated the individual into the project. After this had been resolved, time could be taken to explore the more mundane, but probably more important long-range concerns and needs of the participant. The help provided was not so easily proffered nor so rapidly located as it appears to be when recounted in this capsule form. Among the 115 cases there were some greater successes, some failures.

The names are fictitious; the stories are true.

CASE I

Alice Dean, 42 years old, lives with her 64-year old mother in a modest home which they own. Her father died 11 years ago. Alice has cerebral palsy. When she was three years old a series of surgeries was done with the hope of straightening already contracting limbs. These were unsuccessful and she is now badly contorted, cannot sit, stand or care for herself in any way. She is totally dependent upon her mother who has carried, fed, toileted, dressed and loved her since birth. Alice also has severe strabismus, does not have binocular vision. No correction other than cosmetic is now possible and this is not necessary to her peace of mind. Ever since she was four years old Alice has had convulsions (epilepsy) which are now controlled by medication.

Mrs. Dean is a capable home and financial manager. Mother and daughter live on a very small income but are unwilling to seek public assistance. Mrs. Dean is also attentive to the needs of her aged mother and aunt who reside in a nursing home. There are no other relatives in the area who can provide assistance.

A close, congenial relationship exists between mother and daughter. Mrs. Dean takes Alice to movies and local events and on short trips. As a result, Alice remains alert and interested in her world. She is animated, talkative and enjoys visitors.

Alice was referred to the project by a public health nurse who had suggested placement in Fairview Hospital for the Mentally Retarded to remove the burden from this aging mother ("you have devoted your life to Alice"). Frightened by this prospect, both Alice and Mrs. Dean evidenced their fear by verbal attacks on the referring health agency and rejection of any suggestions from its staff. This engendered fear which predominated throughout all early contacts with the pilot project staff and had to be allayed before anything could be done to help. Outside placement or some other solution is, of course, a reality here for the mother cannot continue much longer to give the full care.

Turning to a less inflammatory subject for initial consideration the project staff encouraged a physical evaluation for Alice with a view toward lessening the contractures to allow her, at least, a more normal posture. Efforts along this line were not fruitful, but they gave the staff an opportunity to gain the confidence of the Deans so that the future could be faced again. As Mrs. Dean and Alice gradually realized they were to have a part in any plan developed for Alice's future, they turned their attention to immediate concerns. Mrs. Dean had requested a "sitter" service from a number of agencies but for various reasons none was ever obtained. She also had need for an available medical service to respond to emergency calls. These the project handled.

In order to develop a long-range plan, this family needed help from someone who could recognize and use Mrs. Dean's strengths and resources. Project staff were able to fulfill this need. Mother and daughter were made aware of various types of institutions which provide residential care other than those for the mentally retarded. Alice has been taken by her mother to visit her grandmother in the nursing home and her original depressions and antagonism toward institutions have been reduced to the point where she is able to consider such as an acceptable future. They are now aware that other alternatives are also possible. Mrs. Dean has arranged to establish through her estate a trust for Alice's future. For the present she will continue to live at home.

As the project ended its case management role, Alice's body was still as contorted as before and her vision as bad, her epilepsy still there, but she was registered with a continuing professional agency for periodic evaluation of her status and for home care as needed. Alice was under regular medical supervision and she had made contact with a homemaker agency for a "sitter". Both the mother's and the daughter's attitudes toward the future are far less fearful and stressful. They feel that they can, with help, control their future.

This family needed no financial assistance, but they did need help which was nowhere else available to them. The project gave them the support and guidance they needed in solving their problems, nothing more, but this help came at a time when the family was facing total demoralization. Alice will need further help in accepting and adjusting to placement outside her home when the time comes, but that time has been considerably delayed.

CASE II

Rolando Garcia, age 39, was paralyzed from the neck down following a diving accident as an adult. Mr. Garcia is a veteran and receives medical care through the Veterans' hospital. He is separated from his wife and children. He has considerable spirit; his many interests in life keep him alert. He is a cooperative participant in physical therapy treatments and travels on alternate days to the VA Hospital for bowel and bladder treatments. Hence his medical regimen keeps him active.

For several years, Mr. Garcia and another quadriplegic veteran shared a small, somewhat run-down house, the services of a devoted daytime cook-housekeeper-attendant and a nighttime attendant. Both were receiving Veterans' aid, attendant assistance and Social Security disability benefits. This was insufficient to meet their rent and attendant needs. A night attendant who was shared by both men quit when Mr. Garcia's roommate required hospitalization. Mr. Garcia decided to make every effort to maintain his independent housing arrangement; he was determined not to live his life within a hospital.

At this point Mr. Garcia sought the help of the project for there seemed no hope of obtaining another attendant to whom he could offer only $75 a month and no place to sleep. A Mexican employment agency which he had contacted told him that he could not hope to import an attendant even from Mexico for less than $150 a month. Helpless, he was dependent on untrained friends and sympathetic neighbors. The alternative was to place Mr. Garcia in a hospital or nursing home at much greater expense and much against his will.

With counseling and through careful management Mr. Garcia was able to pay his rent, a previously shared expense. With a $50 monthly supplement from the project he was able to hire a night attendant for $125 a month; a college student was willing to come after the project bought a couch for him to sleep on. Mr. Garcia was also encouraged to apply for ATD benefits.

In attempting to help Mr. Garcia out of his plight, project staff found that his teen-age youngsters visit him frequently. Although these visits are important to him, they disrupt the household and upset the daytime attendant to the point that she too was threatening to leave. She receives only $300 a month to care for Mr. Garcia and run his house. Frequent counseling was needed by all to "smooth things down".

Once he was helped through this crisis and given counseling at intervals to prevent other crises, Mr. Garcia, who is patient but persistent when depending on others to expedite matters, learned from the staff about resources available to him and how to apply for them. He is still independent. His present care is less expensive to the community than institutional care and he is now in a better position to maintain a stable state.

CASE III

Shirley Sims, now 26, was paralyzed in her upper body and limbs by polio when she was 12 years old. She can walk if helped to her feet. After abdominal muscle transplants, with the help of a body brace she can maintain an upright position. She has some finger dexterity, but very little strength in her arms.

Mrs. Sims was helped to complete college by ATD and Vocational Rehabilitation Services in another state which she did with honors, after which she moved to California. She was not eligible for ATD until she had been here three years. This left her unable to have an allowance for an attendant.

Two years ago Mrs. Sims married. Her husband is employed full time and attends college. The couple live in an attractive three-room apartment. Her mother, employed in the evenings, was unavailable to provide care during Mr. Sims' absence at college. If he gave the care, it slowed the completion of his education. The arrangement arrived at was for Mrs. Sims to be taken to her mother's who provided the care during the day. This task, along with working full time and caring for two teen-age sons, so overburdened the mother that family friction resulted. This was the situation when Mrs. Sims became a participant in the project.

Shirley called the project after reading about it in the newspaper. A quick review of the situation indicated that help must be provided if a far worse situation was to be averted. The project agreed to pay for an attendant until Mrs. Sims became eligible for ATD assistance. She immediately advertised for, interviewed applicants and hired an apparently capable and compatible attendant; she began to carry out her plans to be a housewife and homemaker for her husband. For one year the project paid for the attendant, who received $1.50 an hour in addition to her Social Security benefits. The attendant lifted, bathed, dressed and groomed Shirley. She prepared meals, washed dishes, cleaned the apartment and ironed clothes. She took Shirley with her to the laundromat and while the clothes were washing they shopped for food, clothing and other supplies. The attendant used her private automobile to provide transportation to the stores, to the doctor's office and to Rancho Los Amigos Hospital.

Mrs. Sims is an astute, pretty, young woman, with a remarkable ability to interview and assess people. She communicates well and had hoped to continue her education to become a social worker. This may be a future possibility. In the meantime she has learned to sew and do some meal preparation and is developing budgeting and purchasing skill. She has decorated the apartment and made it a home. Encouraged by the project staff, she and her attendant volunteer time each week to a nursing home helping five other similarly but more severely handicapped young adults. Mrs. Sims has emancipated herself from unwanted dependency on her mother and has begun to contribute to her family and community.

With an attendant in the home Mr. Sims was able to change his work time to evenings and go to school during the day, thereby accelerating his education. The advantages to the other family members have been multiple. Her mother and brothers have been more helpful to her since they are no longer overburdened by her care. Family relationships have improved and they now have frequent family weekend outings. When Mr. Sims completes his education, this family may no longer need public financial assistance.

CASES IV AND V

Both George Holton, age 27, and Andrew Mayhew, age 53, have cerebral palsy. Mr. Holton must use a wheelchair, but has considerable control of his upper body. He can and does drive a specially-equipped car. He has lived with his parents since birth, attending schools for the orthopedically handicapped and graduating from junior college with an AA degree in journalism. Before 1967 his income consisted of $40 a month earned at Goodwill Industries. He does not want public welfare and a savings account makes him ineligible. A Social Security payment as a disabled dependent of his retired father now provides some monthly income. Except for Vocational Rehabilitation Services, Mr. Holton had not availed himself of community resources.

Mr. Mayhew requires a "walker" frame to navigate short distances; for longer expeditions he operates an electric autoette. He too depended on VRS to supply him with needed services until late 1967 when he became eligible for ATD assistance by meeting the residence requirement. Until 1964 he lived in Arizona, where he ran a small sundry goods store. When other members of his family died, he felt need to be near an able-bodied relative, so he came to California where his married sister lives. He was adamant against leaning on her for financial support, and he tried working at Goodwill Industries. On weekends he visited his sister, who did his laundry, gave him food to take home and was generally helpful. The work at Goodwill Industries for which he received $40 a month soon proved to require more manual dexterity than he had and he wanted to quit, but the work exhausted him to the extent that he had no energy to seek other employment more fitting to his abilities. While waiting out his eligibility for ATD, the only avenue apparently left open to him, he gradually used up his savings.

At Goodwill Industries he met George Holton. Both men were discouraged; gainful employment seemed remote; self-sufficiency seemed unattainable. At this point Mr. Mayhew applied to the project to help him find a way to use his mental ability.

After considering all resources, it was decided to provide Mr. Mayhew with $70 a month for a short time so that he could experiment with various ways of making a living. Recognizing the employability and strong motivation of both Mr. Mayhew and Mr. Holton, project staff worked with them to assure maximum training and suitable placement. After several months of volunteer work and agency contacts they learned of and became interested in a small business using copying and addressograph equipment; they applied to VRS for training. Their first contacts with VRS were discouraging, but aided in their perseverance by project staff, they were finally allowed to enroll in a training program. Mr. Holton and Mr. Mayhew were regarded by VRS as the most disabled of the many persons trained throughout the country; nonetheless they were trained.

With some of Mr. Mayhew's savings and financial assistance from Mr. Holton's family, they were able to open their own business. In the short time they have been operating, they have not yet made a profit, but the business has provided a focus for constant self-improvement and confidence. Both men dress neatly, get to work punctually, and have developed several practical ideas to extend the enterprise into more profitable avenues. Frustration of futile struggles no longer plagues them.

During their time on the project the staff gave attention to the medical and dental needs of these men as well as supplemented Mr. Mayhew's income for a short time. They counseled and served as "advocate" for them at a time when both men felt they could no longer wrestle with public agencies skeptical of their ultimate working abilities. In return two dependent men have been readied for self-sufficiency, with every prospect of success. Both are adamant in their desire to live and participate in society - not escape into institutional care.

CASE VI

Rosa Benifez, the sole support of her three children, worked as a domestic. One day as she paused to rest on a second floor balçony, the railing gave way and she plummeted to the sidewalk below. Both thigh bones and both knee caps were compoundly fractured, and the spine in the neck was injured. Infection developed in the left thigh bone and she was hospitalized for four years. She had fair return of use of her right side and, in 1962, was discharged from Rancho Los Amigos Hospital in a wheelchair. She returned to a rented home and children on ATD and Aid to Families with Dependent Children (AFDC) assistance. At that time a ramp was needed in order for her to manipulate the wheelchair safely, but Rancho could not build one onto a rented house.

Four years later a nurse from the VNA referred her to the project; the referral was for a ramp. In the interim she had several times toppled off a still extant makeshift ramp, a plywood board placed over a broken door frame laid across steps at an angle of 45 degrees. At least twice she had received injuries serious enough to be taken by ambulance for emergency treatment.

By the time the project encountered Rosa, at 33, she had six children. They existed in a run-down two-bedroom house surrounded by tall grass. The screen door was broken and the shades were tightly drawn. Inside there was some second-hand furniture, and only two beds and a sofa for sleeping. The refrigerator did not work properly, so daily shopping was necessary. Meals were taken in shifts because there were only two chairs. The furnace did not work. The unfinished floors were rotting from frequent wetting to keep the dust down. The children had frequent colds. Rosa stayed in bed most of the time, though she had left the hospital able to get about; she spoke only in Spanish and had very limited patience with her children, sighing over and over "I wish I were dead". Mr. Benifez had recently been in prison and found great difficulty getting work. The family lived on public assistance. Any money earned by Mr. Benifez was deducted from the sparse monthly allotments. The family was unable to buy enough clothes to go around, let alone improve the house.

Initially suspicious, Rosa insisted for weeks there was nothing she or her family needed. The project nurse persistently and patiently stopped by weekly, knowing that she had to convince Rosa by her actions that she thought her a worthwhile person and that someone cared about her. Christmas was coming and when the nurse found that the ATD and AFDC workers could not assure her that the family would receive any gifts, she used her own money to buy gifts for each member of the family.

The ice was broken. Slowly Rosa developed some trust in the project staff, the behavior of the entire family improved and Rosa stopped sighing "I wish I were dead". She listened and heeded when the nurse explained directions on medications and why it was important to follow directions. Medicines began to be used. When no other resource was found, project funds were used to help build a safe ramp and to enable Mrs. Benifez to buy a refrigerator and washing machine. A sewing machine donated through the project was repaired and Rosa now makes many of the children's clothes. New curtains were hung at the windows. The yard was cleaned by the family. The grass was cut and watered. Funds were provided for a dinette table and eight chairs proudly selected by the family. This purchase revolutionized their lives. They had meals together and invited relatives to visit. A Health Department sanitary inspection, suggested by the project staff, prodded the landlord into repairing the faulty furnace. When Mr. Benifez was beaten and robbed of the rent money, the project staff helped him to arrange payment over several months.

Now Rosa speaks English. She is able to cooperate constructively with her AFDC and ATD workers and to plan for family needs. She gets about, goes to school events and actively works with her children in the Head Start Program.

The dismal, hopeless atmosphere has given way to laughter. Affection is shown and pride expressed in each other's accomplishments. The children respond to Mr. Benifez's authority, perform better at school and are more helpful at home. Future plans include physical therapy for Mrs. Benifez to help her regain the degree of activity she had before she retreated to her bed.

The family has been rescued, at least temporarily, from its rapid course toward destruction. Mr. Benifez now needs employment. With a regular income from him, this family can lose its dependence on AFDC, and the assistance from ATD can be used more effectively for Rosa's health and to keep this family intact. The project staff has counseled Mr. Benifez on how and where to search for a job. But there must be further counseling and guidance if the moves toward self-reliance are to continue. The project has had to end its assistance to this family.

CASE VII

Dayton Jones, 28 years old, has cerebral palsy. Limited in his physical powers, he has been encouraged by his parents, both of whom work, to use his mental capabilities. They have moved and made other adjustments in their lives to educate Dayton and he was graduated from college last June with a degree in journalism. He has published several articles and has photographic skills.

The Jones family had good knowledge of available community resources, but believed that they were not eligible to benefit from them. In spite of his excellent employment potential, the Vocational Rehabilitation Service had given Dayton only nominal counseling and some funds for transportation, books and other educational expenses. The VRS counselor did not see him for three years. Consequently, Dayton did not request further service for he felt he was considered a poor risk.

Families of "means" and strong social functioning may be "forgotten" by agencies. The project staff was able to demonstrate the importance of reevaluations and persistence in obtaining help. They reinitiated the interest of VRS and also because they felt Dayton would benefit from physical therapy which he was not receiving, they helped him to apply for assistance from ATD. Through his doctor he was referred to a rehabilitation center for new equipment - braces, lift and wheelchair.

Though initially skeptical, the center found Dayton diligent and responsive to new procedures. He mastered placement of leg braces alone, improved the quality of his transfer from the wheelchair and passed his driver's tests. His parents agreed to buy him a suitably equipped car, and he became so skilled at driving that the driving school is considering using him for a training film. Dayton's aspirations have focused on becoming more self-sufficient. He feels the project gave him an important step toward independence by helping him to deal with agencies. He no longer leaves such responsibilities to his parents and has demonstrated that he can and will persist to obtain needed services, as witnessed by his persuading his current VRS counselor to let him take a course in computer programming. This modest investment provided immediate and stimulating employment. He is now employed full time by his instructor.

This family needed no money. They did need and made good use of the project's assistance once it became available to them. Through it a handicapped person has been made self-sustaining and can live with dignity.

CASE VIII

Helene Holman, age 20, was an accomplished pianist, a college student and a salaried typist before brain tumors and their surgical removal transformed her life. Paralyzed on one side and totally deaf, she had been rejected for vocational training as being "too seriously involved". Helene lived with her overindulgent and overprotective parents, who disagreed with the estimation of her potential. Caught in this conflict, she found it impossible to plan for the future. When frustrations from the isolation of deafness and partial dependence mounted up, Helene had violent temper tantrums.

Project staff found Helene's case challenging because of her strong motivation despite the confusion surrounding her potential. Adjudging her worthy of reconsideration, the project staff consumed much time and effort in intervening on her behalf with hospitals, vocational rehabilitation counselors and her physicians to expedite her reevaluation. Even with "advocate" prodding, it took many months for agencies to act on her case.

Although no hope was expressed for her physical improvement, Helene was instructed by project staff in additional self-care tasks which she had not been doing. Psychiatric treatment was secured for her through which she mastered better self-control and further vocational rehabilitation was recommended. She taught herself to lip-read and took a correspondence course in accounting. The project staff rented an electric typewriter for her so she could pursue her studies.

Success in eliciting cooperation from health professionals and support from the project staff resulted in Helene's determination to live independently. Despite intense parental objections, she was able to develop a plan to share housing with a nurse friend and a daytime attendant and to return to college.

CASE IX

Frank Powell, age 40, had always held more than one job to support his family. Driving while overtired from his labors, he had an accident which broke his neck. Although he is now classified a quadriplegic, Mr. Powell has total sensation and can walk with assistance.

Mr. Powell lives with his wife and children in their own home. The marriage is stormy and unstable with frequent separations and reconciliations. After discharge from the hospital, Mr. Powell was plagued by gross financial problems. Mrs. Powell's salary was augmented only slightly by public assistance. Mr. Powell was eager to work, to earn money and to reassume the dominant role in his family. Because the family was in bad straits and he needed care he was not receiving, Mr. Powell was referred to the project.

The project staff had a ramp and physical therapy platform built for him and enabled him to repair his car so that he could be driven to the hospital for needed medical care. They counseled the family extensively and with profit. Project funds provided a monthly financial supplement until Mr. Powell became eligible for ATD assistance and a loan of $90 was made toward purchase of an electric typewriter to enable him to write business letters.

Like most quadriplegics, Mr. Powell does not perspire easily. Excessive body heat may produce fever and death. His request for an air cooler could not be filled by any public agency so project funds purchased one. Eventually combined ATD and project funds purchased him attendant care.

With his physical amenities under control, Mr. Powell was then able to concentrate on employment. Helped by the Vocational Rehabilitation Service, he established a "Do-It-Yourself" automobile repair garage. The VRS financed most of the business costs but the plan nearly failed at the last minute because of that agency's restrictions. It was necessary that a toilet be installed on the business premises before permission could be given to open the garage. Vocational Rehabilitation Service could not spend the needed $25 for this because it would improve someone else's property. The project paid this expense and thereby made it possible for Mr. Powell to open his own business. The garage provides him with daily incentive, financial rewards and improved self-esteem. It capitalizes on his own skills as a mechanic and saves his customers money by enabling them to repair their own cars. Mr. Powell is now channeling his energies into stabilizing his shaky marriage with the help of the local Family Service Agency which he was willing to accept after project counseling and referral. The future looks promising for this family.

A fairly large financial investment in this family was made by the project. If economic independence and preservation of the family is achieved, the investment will have been far less than the continued welfare expenditures.

CASE X

Carol Dana, age 25, has cerebral palsy and is a spastic quadriplegic. She lives in a wheelchair which she propels backwards with her legs and is dependent on others for full-time personal care. She is active, resourceful and ambitious; wants to keep busy and be useful. She is eager to live an adult life independent of her parents, feels that she has been a burden to them long enough, and wants to free them to enjoy their remaining years in privacy and with freedom to travel. Miss Dana was referred to the project after she had combed the State for a resource that might answer her purpose - a "boarding home for young handicapped adults" - and found none.

The Danas did not reside in a project area, but the project staff corresponded with her. They found her to be highly motivated and to have a realistic appraisal of her abilities and limitations. Since her potential for relatively independent living was high and since she planned to move to Sacramento, they offered to help. With the cooperation of the Welfare Department in her own county and in Sacramento the move was made. Here the project staff helped her to locate a suitable apartment where she could have access to community resources and recreation. They recruited and screened prospective attendants for her. From among them Miss Dana made the final selection and project staff then helped train the chosen one. A tutor was hired to improve her reading ability for Miss Dana's early education had been irregular.

Project staff evaluated her medical and other needs and encouraged medical care. Project funds purchased needed medications, unavailable through Medi-Cal. A bathtub lift was needed and the staff assisted Miss Dana to obtain it through Medi-Cal.

With these services, her independent living became a reality. Miss Dana then put her energies into organizing a Young Physically Handicapped Club. With additional educational and social involvement, she expects to keep herself mentally occupied. With careful attention to her physical needs, Miss Dana can expect to live a normal life span and should be able to contribute to society. Through the project she was made aware of her physical care needs and how to obtain good care.

Miss Dana has now returned to her own county but not to her parents' home. She is living in an apartment with her attendant. Her desires for independence, for the right to make her own decisions, control her future, live in her own home and be a part of the community, typify the reaction the project staff met so constantly from mentally normal handicapped persons. Through her story it is possible to show how many of them - the vast majority - can be helped to remain in the community. With proper evaluation and provision of services in the home this is readily possible.

TOP: Two project participants, each with severe cerebral palsy, were not able to find suitable employment. With the help of the pilot project and other organizations they were able to start a small business that they expect will make them self-supporting. BOTTOM: A paralyzed college student is preparing himself for the future, with the help of good care and a good family home. Three years earlier his neck was broken while diving in a neighbor's swimming pool.

TOP: With special equipment and much effort, a project participant is able to read about the world outside the nursing home in which he lives. RIGHT: Independence is important to a man of 37 who, with help, is able to maintain his own apartment. BOTTOM: Special training, and special devices, enabled a severely handicapped man to drive a car. With transportation, he was able to obtain employment as a computer programmer.

HEALTH CARE

From a medical point of view, the severely handicapped lead a peculiarly precarious life. If they are to survive the emergencies and serious acute illnesses to which they are so prone, they must have constant access to various and often highly specialized types of medical and paramedical services.

The project found that physically handicapped persons have great difficulty finding physicians willing to accept them as patients for continuing care, although care for acute illnesses is apparently as readily available to them as to the general public. Many of the participants who did have physicians for regular, ongoing care were in the hands of practitioners who saw them seldom, who would not make house calls and who lacked training in neurology or physical medicine essential to the adequate management of the patient's particular condition.

Essentially all participants had had some form of medical or health care, Table XIV.

Table XIV

PERCENT OF PARTICIPANTS BY SOURCES OF HEALTH CARE

SOURCES OF HEALTH CARE	PERCENT
Total	100
No Consistent Care	2
Private Physician, only	26
Clinic or Hospital, only	29
Private Physician, Hospital Clinic and/or Rehabilitation Center	39
Other (Nursing home, Chiropractor, Christian Science Reader)	4

The majority received some care from physicians, but over one-third of the participants had no private physician. Over half used some institutional resources. Although at least 90 percent were living in their own homes or situations in which home care services would have been appropriate, few of them were known to or were receiving regular care from home health agencies.

Project staff observed that not only physicians but other health professionals tend to turn away from the severely handicapped. Many of those giving care had limited knowledge and experience to equip them for the management of the severely handicapped. Only a few were indifferent or unsympathetic. Some were restricted by agency policies in the type and/or amount of care they could give. In the minds of many the "stereotype" of the severely handicapped, built up over the years, established an artificial barrier to providing effective care. Some project staff members, themselves, had to discard their "stereotypes" before they could become productive.

The ongoing care of the physically handicapped is essentially preventive care, very different from hospital care. Ongoing care attempts to prevent the occurrence of damaging and costly acute complications and to prevent deterioration in physical and social functioning, thus obviating the need for very costly services such as surgery or further rehabilitation and remedial case work. An important observation of the project staff was that few participants were getting sufficient ongoing care of a quality to serve this preventive purpose. Of particular importance to handicapped patients is good discharge planning on the part of hospitals and rehabilitation centers, the process by which proper placement for ongoing care and assurance of continuity of care is accomplished. Unless it is planned and specifically arranged for, post-hospital care is likely to be haphazard, fragmentary or nonexistent. Although in recent years there has been a drive to establish discharge nursing or so-called liaison-nurse positions in hospitals, there are still many medical care facilities, including those with rehabilitation units, which lack them.

By attempting to supply adequate ongoing care and in some cases actually giving the care, the project staff learned that a team of qualified professionals, well trained in rehabilitative techniques, is mandatory for adequate ongoing care. Under supervision of a physician the minimum required is a nurse and a medical social worker with other paramedical disciplines of a wide variety available as needed. The project staff found such teams, accustomed to operating as a unit, available in many communities in coordinated home care agencies and sometimes in hospital and rehabilitation clinics. For the most part, however, these teams were insufficiently trained in the special needs of the physically handicapped and/or insufficiently coordinated in their functioning to be effective without assistance from project staff.

In addition to the usual nursing responsibilities in a home care program, the project found that nursing service needs to be directed in particular toward the prevention of bed sores, proper bowel and bladder care, prevention of kidney stones, prevention of infection, prevention of loss of physical function, instruction in the use of equipment and instruction of family members or others in the care of the patient. Counseling in all aspects of health care is needed. Because the health problems of the severely handicapped are so intimately intertwined with their social problems, care in the one direction without contemporaneous care in the other is usually of little avail. Skilled social work counseling and casework is essential.

It takes time for a newly handicapped person to learn about his disability, accept it and adjust to his changed physiology and new way of life. Some participants estimated that it takes at least two years for this adjustment to be completed. Obviously, some had taken much longer; others had never adjusted. During the period of adjustment health and social counseling can be particularly beneficial, even though the family may be well able to furnish whatever physical care is needed.

The project staff found that even with qualified personnel to determine his need and to plan, coordinate and actually give ongoing care, unless the patient himself is involved in decision making concerning this care, it is likely to have little lasting benefit. Such patient involvement is not customary in medical practice.

ATTENDANT CARE

Much of the personal care of even the very severely handicapped can be and is given by nonprofessional workers both in institutions and in the home. This is safe provided that someone with medical knowledge evaluates the patient first and decides what care is needed, how much, and what portion of it can be given by a nonskilled aide or attendant under professional nursing supervision. Giving a physically handicapped person too much help can be more damaging to him than too little help. More physically handicapped persons have been returned to rehabilitation centers because they were not encouraged nor allowed to do as much as possible for themselves than have been returned because they were doing too much. Ignorance, kindness, sympathy and, for families, even a sense of guilt often lead to overprotectiveness. It is essential that the medical condition and care of the physically handicapped be reevaluated at appropriate intervals because their condition is not likely to remain static for very long.

Almost every very severely handicapped person requires care by an attendant or aide. Unquestionably, help of this type plays an essential role in keeping such persons in their own home. For the majority of participants in the study this care was provided by family or friends. About one-third (40 participants) had paid attendants, payment coming from either government or private sources, Table XV. The average pay of the 40 attendants was $1.08 per hour, a low figure considering the responsibility involved. Fourteen of the 40 attendants averaged less than 50 cents an hour.

Table XV

SOURCE OF PAYMENT FOR ATTENDANTS

SOURCE OF PAYMENT	NUMBER
Total	40
ATD Cash Grants	23
AFDC[1] (part of allowance)	2
Other Government Sources	3
Family	12

[1] Aid to Families with Dependent Children.

The maximum cash allowance any client may receive from ATD with which to purchase attendant care is $300 per month. The average monthly allowance among project participants was $215 a month, an amount inadequate for the need but relatively high compared with the statewide average of ATD allowances, around $100 a month. Six participants paid their attendants more than they received for this purpose, the difference coming from their basic need grants.

Largely because they are so poorly paid, those who work as attendants are untrained and inexperienced. They often give care which should be given only by a trained nurse. They are hired, trained and supervised only by the handicapped person. They work long hours at difficult and sometimes unpleasant jobs. Some so employed are morally, psychologically and physically unsuited for the work.

For these reasons, the quality of attendant care observed in the project was often poor and, in some instances, dangerous. Some attendants were outstanding, had been trained in or through long experience had become proficient in caring for a particular handicapped individual to whom they were devoted. Others were unreliable and had unstable work patterns. When attendants quit or did not come to work, participants were left stranded. Those on the project could and did call the project staff for help at such times. Others have no such recourse.

On the other hand, the project staff found that some attendants who were unskilled and unable to find other employment were forced to submit to mistreatment, inconsideration and various vagaries of the patient or family. In these cases attendants had no one to turn to for support.

Project staff found that families who were giving the required personal care often were breaking under the strain of constant care without respite. Other families not now giving care could have and would have done so had they had some supervision and training and been assured of some relief.

In looking for some community agency to train and/or supervise attendants, project staff found little help. Some of the rehabilitation centers train an attendant for and with a particular patient before the patient leaves the hospital, provided that the family or patient hires the attendant. This is often little help because paid attendants tend to be a mobile group and many soon leave the patient for whom they were trained.

Home nursing agencies are reluctant to train attendants who have not been screened for the job and who are not affiliated with a health agency because the instability of workers makes it a never-ending task.

These same agencies are kept by their legal counsels from supervising the work of persons not employed by them because of the liability factors involved. An agency can supervise family members without the same legal implications involved in supervising paid attendants.

Project staff found that those who give care, whether they are trained or untrained, family member or paid worker, are generally ignorant of the preventive aspects of personal care. For example, a quadriplegic was seriously burned - second and third degree burns - by hot bath water. The attendant, unaware that such patients have no sensation over most of the body, assumed that the water was not too hot because the patient did not complain. Other quadriplegics were found with developing bedsores because untrained and unsupervised attendants did not recognize the need to turn them at frequent intervals. The importance of routine bowel and bladder care was not recognized and failure in such care causes major problems.

Of equal importance were the many procedures which require the services of a professional nurse or physical therapist and which project staff found attendants attempting to do, ignorant of their import.

Problems with attendant care loomed large among those encountered during the course of the project. Where participants were having difficulty securing and keeping an attendant, project staff assisted by advertising for and interviewing candidates. The handicapped person was frequently unable to select an adequately qualified or the most nearly qualified attendant, because he did not know what qualifications to look for or how to judge them. When staff screened out unsuitable candidates, participants were quite able to choose from the remaining candidates ones with whom they were compatible. In a few instances the project supplemented, by a small sum, the pay offered to an attendant where this was essential to get adequate care. In two or three instances the project staff found it necessary to pay for an attendant until the client became eligible for ATD.

Implementation of the new legislation, S.B. 719, creating homemaker services in all counties to supplant attendants, will solve some of the problems of attendant care, but for the severely physically handicapped it will create many more unless certain exceptions to the regulations and certain special provisions are made for this group. With the new homemaker services as now proposed, all nonprofessional personnel caring for the handicapped who receive welfare assistance will be recruited, trained and hired by an agency and will presumably work under professional supervision. These are all plus features to both client and worker. On the other hand, under the $300 a month per client ceiling on services, no handicapped person will be able to receive full-time care or even full daytime care at home from a homemaker-home health aide. Many of them, regardless of cost, regardless of family circumstances or desires, regardless of any other consideration, will have to be placed in a nursing home, hospital or rehabilitation center.

CASE MANAGEMENT

Project staff found that they could not separate out any one of a participant's problems and deal with it separately. They also found, in the majority of cases, that a single professional worker could not handle a case to the best advantage alone. Because of the physical status of clients there was an overall need for physician supervision. Those participants not under supervision suffered unnecessary medical complications. Some of them and/or their families lived in constant fear of what might occur. Much of this apprehension could be relieved and essential preventive medical care given by enrolling participants with good home health agencies. Unfortunately, many home health agencies are not yet equipped to give the full range or quality of care required by severely physically handicapped persons.

All participants were receiving some amount of personal care services, yet essentially none had had an in-home assessment by a professional nurse of the type, amount and quality of his care needs. As a consequence few were getting skilled care of any type even though it was needed. Many were getting what should have been skilled care, given by an unskilled person. If they were getting care from several paramedical disciplines, the care was uncoordinated and therefore sometimes essentially at cross-purposes. Many were getting unsuitable care. Few had had an in-home assessment of social needs by a qualified medical social worker, yet their medical and social problems were usually so interwoven that one could not be managed satisfactorily without the other.

The project staff found it necessary in most cases for a team of a nurse and a social worker, under the general supervision of a physician, to evaluate the total needs of participants in order to find reasonable, workable solutions to their problems.

Even with this team approach, they found that unless there was follow-up, apparent solutions to patients' problems were seldom lasting. Few clients could continue on an even keel without some supervision. The one most striking and universal need of the handicapped observed in the project was for case management - a person to call, a person to speak for them, a person to get them care at the time they need it. For rich or poor this service does not exist; through no agency, public or private, is it now available.

PROTECTORSHIP

In all their dealings with the handicapped and those who care for them, project staff heard expressed over and over and over again the great concern for the future. What will become of the handicapped? Where will they go on that day when they are suddenly left alone? Pressure to face and find answers to these questions came from the participants themselves, from their parents, families, friends, from persons who have worked with the handicapped and even from concerned and compassionate individuals not directly connected with them. Parent groups have been organized for years with this as their major purpose.

The staff was alert to this problem from the beginning and mindful of it throughout the project. Among the participants they found a wide range of reactions to thoughts of the future. Some were so caught in a morass of present problems that they refused to consider the future until answers were found for the present. Some were so worried about what might happen to them in the future that they could not see the present. Some had been cared for all their lives and could not contemplate any other prospect. Some had already been faced with the problem of no one to depend upon and had found solutions, satisfactory or not. There is no question that the parents expressed the greatest overall concern for the future. This was true regardless of financial status. Many parents had only one unmet basic need - assurance that some provision would be made for the future care of their child when they were unable to care for him.

Project staff, usually after more immediate needs had been satisfied, discussed the future with most participants and also with other handicapped persons and/or their families not on the project. Many parents could only envision a public institution, specially designed, staffed and equipped for the exclusive use of the severely physically handicapped of normal mentality. Most of the participants dreaded the thought of being placed in such an institution.

In their study of this problem the staff found an urgent need for some system of protectorship to be established, available to those handicapped who need it but not forced on those who don't. Some, because of their physical disability, lack of training or for other reasons, are unable to manage their own business affairs. Others are capable of managing these matters, but need protection of their persons. As a group the handicapped are apt to be preyed upon by the unscrupulous. Many of them, having lived sheltered lives, are highly susceptible to being duped when unprotected by family or friends. Others, lonely, rejected by much of society, are willing to take chances beyond their better judgment in return for some welcome attention. Because hope dies hard, the handicapped are often ready victims of medical frauds. Nothing less than true legal guardianship seems to be necessary for some. For others protection which still ensures the individual right of decision making is more desirable and acceptable. All need assurance of ready access to adequate medical care. A system which assures protection without denying basic rights and freedom must be developed. Members of the legal profession are currently considering such a system.

The project staff believe that there is and can be no single answer to the question of assuring future care because of the wide range in physical disabilities, attitudes toward and reactions to these disabilities and in financial status and in other respects. The handicapped and their families must have assurance of a satisfactory place and way to live when they are unable to live at home. Mental hospitals, homes for the aged and nursing homes do not make satisfactory homes for young or middle-aged, mentally alert, handicapped individuals. In such institutions, their total needs cannot be met. To answer this problem a variety of living arrangements suited to the needs and desires of the individuals concerned is required. A system is needed whereby placement is possible, on a fee-for-service basis, in any satisfactory, specially approved, supervised and mutually acceptable residence in which services geared to the needs of the handicapped are provided. This would permit the disabled person and his family to have a choice and a voice in the selection of residence. It would also permit the disabled person to live in a compatible setting, commensurate to his needs, near his own home and in or near the community to which he may have become attached. Such residence might be a group living arrangement, a hotel, a special wing of a nursing home, a modified motel, a private institution, a foster home or, where necessary, a hospital. Any place offering such service should be required to meet State standards much more rigorous than ordinary licensing standards. Although few satisfactory accommodations are now available, as soon as a mechanism for placement and for payment is worked out and standards established, they would become available.

The staff investigated the subject of protectorship and found that the possibilities in this field are now being explored by lawyers, counselors, certain voluntary agencies and others. No solution to the problem has yet been found, nor will it be easy to find. Protection is needed, but that given must not infringe any more than necessary upon the rights of the individual. The project staff can offer no answer to the problem at this time, either. The limits and responsibilities of protectorship must be defined, and a system of providing it must be developed.

HOUSING

Severely physically handicapped persons of normal mentality were found living alone, with family or friends, in group living arrangements, in motels, special facilities for the handicapped, hospitals, rehabilitation centers and nursing homes.

The Pilot Project found that the vast majority of handicapped prefer to live at home or independently in the community, and are able to do so. Some either cannot or do not want to live independently. Generally, they aspire to a protected residential environment with other handicapped persons of similar age and disabilities and with free access into the community. Others, more severely handicapped, need to live in formal institutional settings because of their need for round-the-clock skilled care, their dependence on complicated mechanical equipment, or both.

Although approximately 15 percent of the study group lived in institutions, probably not over 5 percent of the total in the State need the highly protective environment of the hospital or rehabilitation center for survival; perhaps not over 5 percent more need the less protective setting of the nursing home. Many of those now living in institutions do so because they have no other place to go, no one to care for them, or because conditions in their own homes are so bad that at home the patients rapidly deteriorate and are soon forced to return to the hospital for surgery and/or further rehabilitation. After repeated episodes of re-rehabilitating the same patient for the same condition at frequent intervals, hospitals and rehabilitation centers tend to make such patients permanent residents.

Home or Independent Living

There are many reasons why most of the handicapped prefer to live at home or independently. They are not sick people in the usual sense of the word. For them, their infirmity is the normal state; they have either learned to live with it or have never known anything else. They do not require the skilled services of a hospital or nursing home and resent the aura of illness. They have strong desires to be involved in decision making, to manage their own affairs and to contribute to society. Many are deeply attached to their families and would be shattered by separation from them.

Securing and maintaining suitable and adequate housing is fraught with many difficulties for the handicapped. Problems related to housing were mentioned by project participants more frequently than any other.

single problem. Inadequate public assistance allowances or marginal private incomes often force the handicapped into low-rent, poorly built and maintained structures. Many landlords won't accept welfare recipients as tenants. Most public housing excludes the physically handicapped unless he is ambulatory or is attended by a live-in companion.

Most ordinary dwellings have architectural barriers to the handicapped. The project found that an occasional sympathetic landlord permitted and sometimes paid for widening door frames, installing stationary ramps and other adjustments, but many did not. Of the 92 residences occupied by project participants, 55 (60 percent) were found to have some architectural barriers hampering the movement or activities of the handicapped resident. Among these same 92 dwellings, 53 (58 percent) had one or more features which rendered them unsafe for the participant.

If more provision were made for the handicapped - the same provisions needed for the elderly - more could remain in the community. Federal funds are available to public housing managers to make dwelling alterations to accommodate the needs of the physically handicapped. They are not applied for. Funds are also available for public housing especially designed for the physically handicapped. Few housing projects include such accommodations. Hotels and motels have facilities such as community dining rooms, common rooms, shops, movies, convention rooms, ramps, elevators and room service which would be useful to the handicapped. But few of them accept or encourage physically handicapped persons as permanent residents even though some could afford such living accommodations.

Nursing Homes

When first encountered none of the 14 participants living in nursing homes was happy. They were all young adults and their greatest complaint was having to live almost exclusively among the elderly (average over 80 years old), most of whom they did not consider mentally alert. Some participants were not getting all the health care services they needed. Few other services which could have enriched their lives or started them toward a greater degree of independence were available to them. The features of regimentation irked them. They complained about the limited space available and about the absence of even simple provisions for storing personal belongings. Money for essential personal items was insufficient. Despite their unhappiness, however, some expressed fear of leaving because they might fail in less sheltered settings; yet they longed for participation in the outside world.

Those participants who were living in nursing homes because they had been abandoned by their families had great difficulty adjusting. Placement in a nursing home has a quality of finality about it which seems to be reinforced by the circumstance that most of the other residents are elderly and have little prospect of leaving. Discouraged and indifferent to the few opportunities for intellectual stimulation, they had almost "given up".

Administrators of the facilities expressed concern; they were sensitive to the lack of stimulation to young people forced to associate exclusively with the elderly. Their suggested solution was that separate "youth wings", licensed according to the standards for establishments for handicapped persons, be developed in nursing homes. Few such "wings" exist anywhere in the country. They also stated the need for handicapped persons to have more social links to community groups of comparable ages and interests. Project staff found that it took relatively little money but a reasonable investment of staff time to improve perceptibly the lot of the nursing home dweller, both in physical comfort and in state of mind.

The answer to some, but not all, of the nursing home problems can be met by an institution specifically designed for the physically handicapped of mixed ages. Project staff had the opportunity to study such an institution, the one recently completed in Los Angeles by the Spastic Children's Foundation. A detailed account of the project's experience with this residential facility is given in Appendix E.

Group Living

Group living in suitably constructed dwellings or sections of larger institutions has been the goal of many handicapped people. In general, those with similar handicaps as well as those with like interests, have shown a strong desire for such arrangements. Most experiments in group living have failed within a relatively short time for various reasons, many of them related to the fact that there was no non-handicapped responsible person to oversee the operation. Other reasons for failure were lack of initial planning. In their desperation to improve their situation or to get out of an institution, many have rushed into a group setup. Money troubles, need for outside psychological support, incompatibility, unsatisfactory attendant care, serious acute illness in the group, inability to recruit new members when needed and lack of ability to obtain necessary services were other reasons for failure.

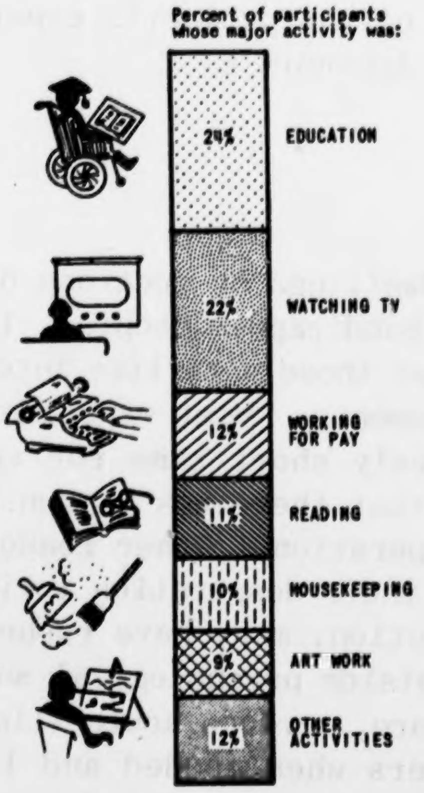
The project staff had opportunity to work at some length with three experiments in group living and to observe several others. Because of the great interest in this manner of handling the residential needs of the handicapped a fairly detailed summary of the three groups studied is given in Appendix E. None of them could be rated as a great sucess.

Despite its poor record, the staff feels that group living, when properly developed, financed, controlled and supervised, has great potential and that it is one answer to the problem of residential care of the severely handicapped of normal mentality. Obviously, there is no single answer to this problem because of the wide range in handicapping conditions and because these people are individuals with minds of their own who will not submit to a single dictated answer.

DAILY ACTIVITIES

The range of activities open to the severely physically handicapped is necessarily limited although often the limit seems to be set or extended as much by the degree of initiative, drive and perseverance possessed by the individual as by his physical condition. Such things as age, place of residence, emotional state, available money and available transportation also influence the range. Nearly anything that the project staff did for a participant resulted in some broadening of the range of activity.

Figure VII
HOW PROJECT PARTICIPANTS SPEND THEIR TIME
JULY, 1968



The project staff found many of its 115 participants expending much of their time and energy on basic activities such as dressing, eating and caring for physical needs. Beyond this they had a variety of interests (Figure VII).

Education was the most common "activity of choice"; 28 of the 115 spent the greatest amount of time in this activity. Twenty-five participants, nearly one out of every five, reported spending most of their free time watching television. Another 13 spent their time reading; 10 occupied themselves with various forms of art work. Working for pay or seeking work was the major activity of 14 participants; another 12, all women, spent their time in housekeeping activities.

RECREATIONAL ACTIVITIES

For young adults with long life ahead, social functioning is important. Learning to get along with people and to keep busy, whether for financial reward or not, influences self-esteem and hope. Those persons whom the project staff assisted to find recreational outlets appeared to request fewer "things" and generally reflected more hopeful attitudes toward life.

Recreational activities in the community are well developed for the non-handicapped; for the mentally normal physically handicapped adult they remain relatively unavailable either because of lack of transportation and finances or because of architectural barriers.

Few public buildings, even those recently constructed, have incorporated the few simple features which would make them accessible and facilitate their use by the handicapped - elevators, wide door frames, wall hand rails, automatic doors, no steps or door sills. To illustrate the problem - making use of the YMCA swimming facility for one disabled person required willingness on the part of his attendant to assist him into the car and drive him to the "Y" and then willingness on the part of the YMCA staff to help carry him and his wheelchair up a flight of stairs.

TRANSPORTATION

Transportation is a major problem for the severely disabled because of their inability to get into or out of conveyances unassisted. Wheelchairs compound the problem and exclude them from conventional modes of public transportation. If denied transportation, the homebound handicapped is automatically limited in his opportunities; for participation in activities such as attending school, training classes, most employment, recreation and church is usually dependent upon one's ability to get to them.

Transportation is possible more or less at will to a few disabled persons able to drive a car equipped with special controls, provided they can afford the special equipment, insurance and operating expenses. Lack of either physical ability or funds closes this means of transportation to most. Many communities lack taxicabs and in some where they are available, they will not serve the handicapped. No community-wide nonprofit transportation pool exists for the use of the handicapped. Attempts at such voluntary services have been abandoned because of the exorbitant liability insurance rates and other insurmountable difficulties. "Servicar" services were available in one study area but were very costly.

Table XVI

NUMBER OF PARTICIPANTS BY MEANS OF TRAVEL
DURING TYPICAL MONTH

MEANS OF TRAVEL	TRAVELED	DID NOT TRAVEL
Total	99	16
Able to travel by auto or station wagon	92	11
Alone with driver	12	1
Alone with driver, but with some assistance	23	-
Must be accompanied	57	10
Able to travel by public bus or trolley	12	-
Alone	4	-
Alone, but with some assistance	5	-
Must be accompanied	3	-
Unable to travel	-	5

Note: Persons are classified by all travel means used.

Most project participants, using one means of conveyance or another, were able to travel from home at least once a month. During a typical month, 99 of the 115 participants were able to and did travel; 16 did not. Of the 16, 5 participants could not travel at all except by specially equipped ambulance or hospital vehicle, Table XVI.

Seventeen participants were able to drive automobiles, station wagons or "minibusses" equipped with special controls and other special devices. Eighty-four percent of the participant group use wheelchairs. Taxi drivers frequently refuse to lift them from wheelchair into taxi. A handicapped child attending school in Long Beach did not encounter the difficulties met by handicapped adults; however, taxi drivers would lift young children but not their wheelchairs. Increased auto insurance costs for drivers handling the handicapped was given as one reason for their refusal to lift.

For young handicapped adults the desire to get out into the community is sometimes so strong that they seek out or develop very unusual means of transportation. One such group living in a nursing home in Long Beach was unusually anxious to "get into the world". A severely disabled member of the group, who operates his electric wheelchair with a finger control, saved money from his veterans' disability pension to purchase a used telephone repair van. He designed a lightweight ramp to give ready access to wheelchairs and with the assistance of a friend, who translated his design into a working model, adapted the van to accommodate two electric wheelchairs. Project funds paid for the ramp when no other payment source could be found. Now the van owner and one other wheelchair patient are able to take short trips with an attendant and driver.

EDUCATION

Education offers the greatest opportunity for life enrichment and the only chance for possible employment of the disabled. The educational attainments of participants were discussed earlier. The project staff found many unavoidable, but also some unnecessary, barriers to the pursuit of education by the physically handicapped of normal mentality.

By relatively simple and inexpensive modification of school buildings, such as installation of wheelchair ramps and handrails in toilet areas, grammar and high school education could be opened to many not now being educated to the full extent of their capabilities. Few buildings have these modifications. Legislation passed at the 1968 session of the California Legislature requires that new schools and other new public buildings be designed for use by handicapped persons.

Often, relatively minor changes in existing school housing and buildings could make possible on-campus student residence for the physically handicapped. A few colleges and universities have made such accommodations. Project staff observed the accommodations for a wheelchair group of students attending the University of California at Berkeley who live in a special section of the infirmary.

The number who could be educated would be increased by providing school counselors, social workers and nurses with the specialized skills needed to work with severely handicapped students and by broadening the range of children admitted to specialized classes to include those with bowel and bladder problems and those who need special equipment. Provision of courses for the handicapped equal in standards to those for the non-handicapped could increase their potential. Development of continuing education programs geared to the needs of physically handicapped adults would provide intellectual stimulation and channels for expression of creativity. This would enrich the lives of the handicapped and improve their chances for employment or gainful occupation. Such courses are in short supply.

Organized educational television instruction now makes possible some education of the homebound, but educational television is not widely available nor does it offer a consistent, progressive curriculum.

In short, unless a handicapped person is capable of leaving his home, has some means of transportation, can attend a school with no architectural barriers to his mobility, has no great physical problems which render him "undesirable" in the classroom, has no major problem in communication and has unusual drive and motivation, he is not very likely, at present, to be educated.

VOCATIONAL REHABILITATION

Obviously, opening the door to gainful employment to as many handicapped persons as possible is of prime importance; first, to preserve the self-respect and dignity of the individuals and second, to free society from responsibility for their care.

The Department of Rehabilitation has developed a wide range of services designed to improve handicapped individuals' potential for employment. These services are made available to handicapped persons who are 16 or older and are likely to benefit from them. The mild to moderately handicapped person who demonstrates high motivation and offers some promise of successful rehabilitation to the point of employability, has many opportunities open to him. The severely handicapped, on the other hand, with his paucity of physical assets, is usually not viewed as a good risk for vocational rehabilitation, even though his motivation is as strong and his need for meaningful activity as great. He finds it hard to be given a chance.

Table XVII

VOCATIONAL REHABILITATION SERVICES
RECEIVED BY PARTICIPANTS[1]

SERVICE	PARTICIPANTS
Total	103
Received no services	58
Received some services	43
Education sponsored	13
Vocational training sponsored	5
Assistance in establishing a business	4
Evaluation only	15
Evaluation and referral to a sheltered workshop and/or sheltered employment	5
Other services	1
Unknown	2

[1] 16 years of age and over.

Among the participants in the Handicapped Persons Pilot Project there were 103 who were 16 years of age or older. Most (58 persons) had not sought or obtained any vocational rehabilitation services. Forty-three had applied and received the following services prior to July, 1968, Table XVII.

The Division of Vocational Rehabilitation worked with a few of the severely disabled participants with a great measure of success. The strongly motivated and the resourceful made use of the educational and other services offered. Among the large group who received no services, the severity of their disabilities and the problems involved in obtaining services unquestionably discouraged many from seeking help. Those who were motivated and tried to obtain services first had to convince their interviewers that they could be rehabilitated. Some participants were told, when they inquired by phone, that they were too disabled to qualify; others were told to wait until they were graduated from high school before applying. Rebuffs such as these kept many from trying again.

The project nurses and social workers encouraged 40 participants to consider their own potential for employment and the training assistance needed, because they felt these individuals warranted reassessment. Remotivated by this counseling, 22 were then able to obtain services, either by themselves (7) or with project assistance (15). Among the 22 are 4 of the 5 participants listed in Table XVII who established their own businesses.

Experience from the project reinforces the common belief that many of the severely physically handicapped can never achieve very much in self-sufficiency. But it also suggests that opportunities for self-help are often cut off too soon or are unoffered.

EMPLOYMENT

Many physically handicapped persons could reduce their dependence upon family or welfare if given opportunity to develop or demonstrate their employment potential. It is known that those physically handicapped of normal mentality who have been given a chance to work in the competitive world have a work record above average. Prejudices, fears, pity, insurance regulations and liability, rigid labor union and employment policies and many other factors at times combine to keep them from working. Of the 75,600 physically handicapped persons who applied to the State Department of Employment for jobs in 1967, only 18,200 were placed.

One quadriplegic participant of the project, qualified as a teacher, was forced, because of barriers to his employment, to take a position in a small-town school 35 miles from his home. Therefore, he had to drive 70 miles every day, despite the fact that 80 teaching positions were vacant in his home city, Sacramento. To take this distant position, he needed a specially equipped car which he could not have obtained without help from the project. Without the project he would have been unemployed.

Project staff, after working closely with the participants over a period of time, estimated that 30 of the 91 clients 20 years of age and over had either a fair or good potential for employment in the competitive labor market. Only 14 of these were employed or seeking employment. Among them were two teachers, a social worker, two computer programmers, a typist and five who operated their own businesses. The independently owned businesses ranged from a do-it-yourself car repair shop to an addressograph-multilith service.

In an attempt to learn why more of the participants trained and able to work were not doing so, project staff found one reason was that handicapped persons are often trained for particular jobs or professions based on the trainer's evaluation of the client's aptitudes and physical abilities, without regard to the marketability of the particular training. Certain jobs become popular among the training agencies. For example, there has been an over-emphasis on training the handicapped to become school psychologists and counselors when, in fact, there are limited opportunities in these fields and not all are open to the handicapped.

Before the handicapped can be given full opportunity to work, attitudes in many quarters must be changed, including, in some instances, the attitude of the handicapped himself toward employment. This is not an insurmountable task, but it requires cooperative action among unions, management and government. Since the problems of employability, as well as employment, are not insurmountable, it seems worthwhile to try to find solutions.

SOME ECONOMIC IMPLICATIONS

Costs of treating and caring for severely physically handicapped persons are high. When they cannot be borne totally by the handicapped individual or his family, they must be borne by the public. Project staff, in its close work with the handicapped, was able to assess the effectiveness of existing programs and services.

For nearly all participants a great deal of money had been spent on care and maintenance. This money came largely from the individual participant and his family, from private health or compensation insurance, from Social Security, Medi-Cal and/or other public and voluntary health and welfare programs. Each agency had spent substantial amounts to meet its responsibilities and each had sought to minimize its expenditures. Yet there was little coordination of efforts and little incentive to encourage one agency to help reduce the expenses of another. Instead, there were instances in which one agency sought to reduce its expenses by transferring costs to another, often with the result that total costs were increased. While some costs could not have been avoided or reduced, considerably greater benefits could have been obtained in many cases from the monies expended. This was particularly true of public assistance funds.

The Pilot Project was designed to deal with those who had already been rehabilitated to their maximum, but still remained severely and permanently handicapped.

The costs of medical treatment and rehabilitation are high. In a study conducted in 1960-1961 the initial treatment and rehabilitation costs of 12 quadriplegics disabled by accidental injury of their spinal cords ranged from \$7,000 to \$127,000 and averaged \$29,000 per patient.[1] To these direct costs of care and treatment must be added the costs of additional special equipment, services and facilities needed for life, as well as indirect costs such as loss in income potential for a physically handicapped person and for other family members who may be forced to forgo employment in order to care for the disabled one. Other severe disabilities are no less costly than quadriplegia.

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[1] Symington, David C. and Mackay, Doris E., "A Study of Functional Independence in the Quadriplegic Patient," Archives of Physical Medicine and Rehabilitation, 47:7, (July) 1966, p. 380.

One who has been rehabilitated has generally been brought up to his maximum level of physical functioning and has been taught as much self-care as he is capable of. Rehabilitation is usually the most expensive form of hospital care. Its benefits are beyond price, but it must be followed up by continuing care and reinforcement. Otherwise, the regained functions may be rapidly and completely lost and the disabled person degenerate to his former level. Through lack of preparation for post-hospital care and lack of follow-up after discharge many handicapped persons have been "rehabilitated" numerous times by the same or other rehabilitation centers at great cost each time. Many of the participants of the project were found to have lost, partially or totally, the benefits of rehabilitation; an ambulatory patient would be found to be bedridden; a bedridden patient would be found to have bedsores; a once-functioning limb would be found distorted and useless from contractures. Bed sores, ulcerations of the skin and deeper tissues, are easily prevented through simple skin care and frequent change of position. They require months of expensive hospital care and, often, skin grafting to heal. Hospitals and rehabilitation centers routinely teach patients or families the importance of preventive care before the patient goes home, but it was uncommon in this study to find, once the patient was discharged, any effort made to see that instructions were carried out.

In some homes various kinds of expensive and often specially made equipment, e.g., special braces, hydraulic lifts, were found unused because no one in the home knew how or why to use them. Some families were duped into buying equipment that was totally unnecessary or unsuitable.

More than half (59 percent) of the project participants were receiving some form of public assistance, generally Aid to the Totally Disabled. For 39 this was the sole source of income. Under the ATD program, the maximum monthly allowance, which covers "basic needs" in nonshared housing, is $155.50. An additional $15 for transportation and $30 for restaurant meals may be allowed as "special needs". In July, 1968, there were 125,976 Californians who received ATD cash grants averaging $114.70. Another 13,190 persons were certified as being eligible for medical assistance under the Medi-Cal program, meaning that this number was equally disabled, but had enough income to keep them from being eligible for ATD but not enough to pay their medical expenses.[1] Despite the meagerness of the individual grants, the ATD program spends about $15 million a month and Medi-Cal spends additional millions to help the disabled. Project participants who were receiving ATD grants found their grants, even at the maximum permitted by law, inadequate.

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[1] California Department of Social Welfare, Public Welfare in California, August, 1968, Statistical Series PA 3-107, Table 1.

Even with such large expenditures of state-federal funds in addition to the large amounts of county and voluntary - not to mention private - funds, the needs of the recipients are still not being met. Therefore, it seems essential to look at ways in which these monies are being spent before expending further sums.

Every agency has its own rules, regulations and policies governing use of its monies and services. These are developed to control misuse and to attempt to ensure their best use for the greatest number of recipients. Once adopted, these restrictions are usually applied pretty inflexibly. The circumstances of the severely physically handicapped of normal mentality are such as to make them a unique but relatively small group, too small to be in the minds of the designers when regulations were being written. Strict application of regulations to this group often results in their being offered sums which, though adequate for other welfare recipients, are grossly inadequate for them in view of their greatly increased cost of living. These are the people who, because of their physical handicaps, have perhaps the least opportunity to be ingenious in stretching funds. When they are forced to live under poor conditions they are very likely to undergo such deterioration that great expenditures of health and welfare monies are necessary to restore them to "health". Restorative costs are often far greater than making small augmentations to maximum monthly grants, thus permitting adequate living conditions. But even though increasing the grants would have saved money in the long run, it could not be done because it would have been an exception to the regulations.

Examples could be multiplied showing the inappropriate, unnecessary or inadequate use of funds for housing, education, vocational rehabilitation, drugs, paramedical services and others resulting in poor total care. All of these are hinted at or touched upon in the selections dealing specifically with these factors.

Unfortunately, the administrative procedures of individual programs are such that automatic coordination of their various services for one individual or one family probably never can or will take place.

An answer suggested by the findings of the Pilot Project is the development of a State program to coordinate services and offer case management, thus making the most effective use of and eliminating unnecessary use of available resources, to the betterment of the patient.

PROPOSED PROGRAM

To meet the needs of the severely handicapped of normal mentality as they have been set forth in this report, it is proposed that a State program be established to offer the following services:

1. Professional evaluation and periodic reevaluation of the program participant by a multidisciplinary team to determine health and social care needs.

2. Ongoing supervision (case management), coordination and provision of care through a health oriented community agency which is licensed by the State Department of Public Health according to standards established by the State Board of Health. Such care is to be provided in the place of residence of the individual, including a boarding home, nursing home or other institution when this constitutes the place of residence.

   Care must include preventive care, as well as other therapeutic, corrective or rehabilitative care when needed.

3. Provision of a compatible and feasible place of residence for the participant including, where necessary, residence in an institution for the physically handicapped, a hospital, nursing home, extended care facility, group living arrangement, private home, boarding home or other suitable dwelling place in a community in which adequate care of high quality can be provided. It is the intention to make care available as widely as feasible throughout the State, but it is not the intention to provide the service in an area where, for any reason - lack of facilities in the community, lack of available qualified professional personnel, or other reason - adequate, high quality care cannot be given at a reasonable cost.

4. Provision of attendant-type care by adequately trained nonprofessional personnel under professional supervision in the designated place of residence.

5. Provision for the temporary shelter of the participant with care in an institution or other suitable accommodation in order to provide respite for the family or for any reason for which a temporary displacement is necessary. This may include unusual, temporary living arrangements at home.

6. Provision for protectorship, even to the extent of legal guardianship where necessary, to protect the person and his property against maltreatment, fraud, theft or other harmful acts. This protectorship is to be closely associated with case management.

7. Provision of or repair of equipment housing modifications, furnishings and other items necessary for the adequate care or functioning of the participant.

To organize and carry out this program the following are necessary:

- A minimum staff of a qualified public health or rehabilitation nurse and a medical social worker with clerical assistance to be established in regions of the State, determined geographically and on a population basis to:
    - provide for adequate medical supervision of participants,
    - provide counseling, case management and supervision of total care,
    - seek out, utilize or promote the development of community resources necessary for the care and welfare of participants and coordinate the services for individual participants,
    - assist in the location or development of suitable places of residence or living arrangements,
    - provide consultation, training and assistance to agencies providing care and
    - represent the program in the community or area.

- A small administrative state-level core staff consisting of a part-time physician, public health nurse, medical social worker, health program advisor, part-time statistician with clerical assistance, to:
    - direct the program,
    - supervise and provide consultation to the regional staffs,
    - establish criteria for eligibility to the program,
    - make decisions, in case of question, concerning acceptance or termination of an individual for service,
    - develop, determine the need for and supervise protectorship services,
    - authorize major expenditures for individual patients,
    - work with other government and voluntary agencies and other interested groups to facilitate provision or utilization of services available through them and
    - consider and propose modifications in laws and/or regulations which would facilitate provision of care or services to the severely physically handicapped of normal mentality.

- The program to be open to any severely handicapped person of normal mentality in California under the age of 65; the specific criteria for eligibility developed by the State core staff to be approved by the Department of Finance and the State Board of Health. All services to be available free to those on public assistance and to the medically indigent, and on a full-cost or sliding scale basis for any others who need and desire the service and who can afford to pay for all or part of the service. Funds to be appropriated to pay for care, services,

equipment, repairs and other expenses necessary to provide adequate services to the participant; no use of funds to be authorized until all other sources of payment, including other government programs, voluntary programs, insurance, Workmen's Compensation, private resources and others have been fully utilized or ruled out. Care and services to be paid for on a fee-for-service basis. Fees to be established on the basis of reasonable cost. Competitive bids to be sought for other major expenditures when appropriate and feasible.

Program evaluation, with a report to the Legislature, to be made at three-year intervals.

ESTIMATED COST TO THE STATE OF ALTERNATIVE CARE PROGRAMS

The alternatives to a State program such as that described are to:

- continue with the costly but grossly inadequate system of handling the severely physically handicapped now in operation;
- place them in existing types of institutions, primarily extended care facilities;
- build and operate a number of State institutions for the exclusive use of the severely physically handicapped of normal mentality.

After the initial cost of building or purchasing these special institutions and providing for their upkeep, the cost of operating them is not cheap because of the additional professional and nonprofessional staff and equipment required for the adequate care of this group. The cost of maintaining a patient in such an institution is estimated to be at least twice that of an extended care facility.

Cost should not be the prime determining factor in deciding between these alternatives, but it is an important factor. To compare the cost of institutional care with the cost of a residential care program of the type recommended the following assumptions must be made:

BASIC ASSUMPTIONS

1. Of the estimated 10,000 severely handicapped of normal mentality in need of care in this State, within a single year probably not over 2,000 would need a significant amount of care to be supplied by the State beyond that already provided.

2. Families who can afford to pay all or part of the costs of care for the handicapped, and are now doing so, would continue to do so under any State program.

3. The cost of physician services, drugs and appliances would be about the same whether patients were institutionalized or at home.

4. The Crippled Children Services, ATD, Medi-Cal, Vocational Rehabilitation Service, the Department of Education and other public and voluntary assistance programs would continue their support to the handicapped at the current level and to the current degree.

ASSUMPTIONS RELATED TO INSTITUTIONALIZING HANDICAPPED

5. By institutionalization of handicapped persons, the potential income of families through release of members for employment who would otherwise be tied up in giving care is not a direct monetary saving to the State and need not be considered.

6. Most welfare payments to recipients would automatically stop with institutionalization except for $15 a month, but in cases in which there are dependents, the welfare support would have to continue.

7. If existing institutional care rather than home care were provided, some of the handicapped persons could be placed in boarding homes, most would require care in extended care facilities and a few would require permanent hospitalization. A conservative estimate of the average cost of such institutionalization is $511 per person per month based on the following rates and estimated numbers:

Boarding homes @ $165 per month for 20 percent of handicapped persons
Extended care facilities @ $426 per month for 70 percent of handicapped persons
Hospitals @ $1,800 per month for 10 percent of handicapped persons

8. Because of the care available in boarding homes and extended care facilities and the requirements of the handicapped, the need for attendants would not lessen materially from that required for patients at home.

9. If all the needs of the handicapped persons are to be met, those in boarding homes and extended care facilities would require additional paramedical services beyond those now available, conservatively estimated at approximately one-half the amount required by those in a residential care program at home.

10. Those in boarding homes would probably require hospitalization for an average of one to two months a year for treatment of complications. Much of this cost could be avoided if patients were under a program of preventive care.

ASSUMPTIONS RELATED TO RESIDENTIAL CARE

11. The average cost per person on a State residential care program would be essentially the same as the cost per person on the Pilot Project, approximately $1,000.

12. The family or others who care for a handicapped person in the home need a respite of approximately 30 days a year to endure the strain of constant care. The average cost of placing the handicapped person for a month or of supplying respite care would be $426, the cost of care in an extended care facility.

13. Some of the handicapped now at home would require long-term placement in an institution even under a residential care program. It is expected that after evaluation by the home care team, probably not over 150 of them would need such care at public expense.

14. Under a residential care program some participants would be helped to gainful employment, thus reducing the public welfare support costs. This is not likely to happen with the patient in an institution. Assume that only five percent of the total 2,000 were successful, release of welfare and other public funds formerly paid for their support and care should amount to at least $400,000 per year.

ASSUMPTION RELATED TO SPECIALIZED INSTITUTIONS

15. If care is provided in a specialized institution for the severely handicapped but mentally normal, such care would cost 1½ to 2 times the average cost of existing institutional care.

Under these assumptions the following relative estimated costs to the State have been made:

REGULAR INSTITUTIONALIZATION

2,000 persons @ $511 per month (Assumption 7)	$12,264,000
One month hospitalization for those in boarding homes (Assumption 10)	720,000
Cost of other special services (Assumption 9)	900,000
Subtotal	13,884,000
Saving of State's portion of ATD grants (Assumption 6)	-1,860,000
Total	$12,024,000

The cost to the State would not be quite as high since certain programs such as ATD and Medi-Cal are jointly financed with both State and Federal funds. Taking this into account it would roughly cost the State a total of $8,000,000 per year or $4,000 per person in addition to what is paid from other sources.

RESIDENTIAL CARE

2,000 persons @ $1,000 per year (Assumption 11)	$2,000,000
1 month respite care @ $426 (Assumption 12)	852,000
Additional cost of institutional care for 150 persons @ $511 per month (Assumption 13)	919,800
Costs of other special services while institutionalized (Assumption 9)	67,500
Subtotal	3,839,300
Less public funds saved by return to employment (Assumption 14)	-400,000
Total	$3,439,300

The average cost per patient is therefore about $1,719 per year in addition to what is being paid from other sources.

As in the estimate of institutional costs, some of the costs listed here are covered by joint State and Federal programs. If similar adjustments were made, the total cost to the State for a Residential Care Program would be nearer $3,000,000 or $1,500 per person per year. Attention is called to the fact that the State is already bearing part of these costs through other programs such as Medi-Cal. There is some possibility that the cost per person on this program may decrease as greater numbers are added and more experience is gained. There seems little possibility that the cost of institutionalization will go down.

SPECIAL INSTITUTIONS FOR THE HANDICAPPED

2,000 persons @ $766 per month (Assumption 15, lower estimate)	$18,384,000
Saving of State's portion of ATD grants (Assumption 6)	-1,860,000
Total	$16,524,000

The cost to the State would not be quite as high since certain programs such as ATD and Medi-Cal are financed with both State and Federal funds. Taking this into account it would roughly cost the State $13,000,000 per year or $6,500 per person in addition to what is paid from other sources.

No attempt is made to attribute any savings to the State which might accrue from a residential care program by eliminating the need for repeated costly "rehabilitations" of the same patient, long hospitalizations and surgery to correct contractures, treat bed sores, serious infections or other complications and by eliminating the purchase of unnecessary or unnecessarily expensive special equipment and other preventable medical care costs. Nor does this estimate for residential care costs take into account the fact that welfare funds saved by returning handicapped individuals to gainful employment are cumulative over the years they work.

Any comparison of costs of three such methods of caring for individuals must, of necessity, ignore many indirect costs and even some fairly direct costs or savings. Nonmaterial costs or benefits involving such things as disruption or preservation of family life, interference with or development of plans for education of client or family members, avoidance or precipitation of physical or mental breakdown of patient or a family member, stress or peace of mind to client and family from knowing that there is or is not an official program to fall back upon in time of crisis cannot be priced. Certain direct costs to families for food, shelter and care of a handicapped person are not included because they would not be borne by the State under a new program any more than they are now unless the person is a welfare recipient. Welfare recipients lose their basic need grants when they go into an institution. This has been taken into account.

APPENDIX A

Senate Bill No. 934

CHAPTER 1419

An act to add Article 3.3 (commencing with Section 310) to Chapter 2, Part 1, Division 1 of the Health and Safety Code, relating to a handicapped persons pilot project, and making an appropriation therefor.

(Approved by Governor July 15, 1965. Filed
with Secretary of State July 23, 1965.)

The people of the State of California do enact as follows:

SECTION 1. Article 3.3 (commencing with Section 310) is added to Chapter 2, Part 1, Division 1 of the Health and Safety Code, to read:

Article 3.3 Handicapped Persons Pilot Project

310. The State Department of Public Health shall initiate and carry out a pilot project in two areas of the state for the purpose of determining the extent of the needs of severely handicapped persons of normal mentality for residential care and to determine how best to meet these needs.

310.1. In conducting the pilot project, the state department shall provide necessary medical and social evaluations and coordinated residential care, treatment and training services, which will encourage and assist handicapped individuals to achieve their maximum potential for independence and personal development.

The services may include, but shall not be limited to, medical and social evaluations, homemaker services, attendant care in the home, foster home care, and residential care in appropriate facilities. Institutional care shall, however, be limited to care of persons so severely handicapped that other care or services would be inappropriate.

310.2. The state department shall make the services available to a handicapped person or his family if the services are needed to alleviate a substantial impairment to the normal functioning of the individual or the family unit.

310.3. The services shall be purchased from private physicians, allied health personnel, public and private residential care facilities, and from local governmental and voluntary agencies in accordance with policies and standards established by the state department. New residential facilities for the care of handicapped individuals shall not be constructed with any of the state funds which are made available to the state department for the pilot project.

310.4. The state department shall determine from the pilot project the extent of the need for the various services, the costs of providing the necessary services, and the benefits which would be derived from providing the services to handicapped persons.

310.5. The pilot project shall be limited to a period of four years. Services shall be provided as a part of the project to caseloads in the two areas of the state selected by the state department for the project.

310.6. The state department shall establish such policies and standards for the pilot project as it determines are necessary to carry out the purposes of the pilot project and it shall exercise administrative supervision of the services which are provided as a part of the project.

310.7. The state department shall provide medical and administrative direction to the project staff. The project director and other project personnel shall cooperate with personnel of local health departments and other appropriate agencies, both public and voluntary.

310.8. Existing community services, facilities, resources, and funds shall be utilized whenever possible in carrying out the pilot project in order to conserve the state funds which are made available for the project. The resources of the handicapped individual or his family, such as income and savings, health insurance, disability benefits, workmen's compensation, or other assistance, shall be fully utilized before state funds which are made available for the project are used.

310.9. The pattern of the physically handicapped children services programs shall be used by the state department as a guide in establishing standards, medical and financial eligibility, and in the authorization and purchase of necessary services and supplies.

311. The state department shall establish such eligibility criteria for the services which are provided by the pilot project as it determines are necessary to carry out the purposes of the project. It shall work with the Department of Social Welfare, the Department of Rehabilitation, the Department of Education, and other appropriate governmental and private agencies and organizations to develop individual programs of care, rehabilitation and education, and to plan for the future care of each individual for whom services are rendered as a part of the field project in accordance with such person's needs and potential.

311.1. The pilot project shall terminate June 30, 1969. The state department shall submit a preliminary report on the findings of the pilot project to the Legislature by January 31, 1967, and a final report and its recommendations to the Legislature on or before the 30th calendar day after the commencement of the 1969 Regular Session of the legislature.

SEC. 2. The sum of one hundred thousand dollars ($100,000) is hereby appropriated from the General Fund to the State Department of Public Health for expenditure, for the fiscal year 1965-1966, for the pilot project which the department is required to initiate and carry out by Article 3.3 (commencing with Section 310), Chapter 2, Part 1, Division 1 of the Health and Safety Code. The sum appropriated by this section shall, however, be reduced by the amount of any appropriation which the federal government may make to the state for the pilot project authorized under such article.

APPENDIX B

ADVISORY COMMITTEE

John E. Affeldt, MD Medical Director, Department of Hospitals County of Los Angeles Los Angeles	October 1965-December 1966
Luther Bergdall, ACSW Executive Director Easter Seal Society for Crippled Children and Adults of California, Inc. San Francisco	January 1968-
Joyce Brink, MD Chief, Department of Pediatrics Rancho Los Amigos Hospital Downey	April 1967-
Harold E. Conklin Chairman, Continuous Care Committee United Cerebral Palsy Association of California, Inc. North Hollywood	April 1967-
Francis W. Doyle, PhD Chief, Division of Special Schools and Services (Retired) California State Department of Education Sacramento	October 1965-
Maurice I. Gershenson Chairman, Legislative Committee United Cerebral Palsy Association of California, Inc. Berkeley	September 1966-April 1967
Leon Lefson, MA, MSW Chief of Field Support Division California State Department of Social Welfare Sacramento	October 1965-

Leon Lewis, MD Berkeley	October 1965-
Sedgwick Mead, MD Medical Director, Department of Rehabilitation Medicine Kaiser Foundation Rehabilitation Center Vallejo	October 1965-September 1966
Harold Renaud, PhD Chief Psychologist, Cowell Memorial Hospital Berkeley	October 1965-December 1966
Esther Elder Smith, ACSW Executive Director (Retired) Easter Seal Society for Crippled Children and Adults of California, Inc. Hacienda Heights	October 1965-

APPENDIX C

HANDICAPPED PERSONS PILOT PROJECT-ELIGIBILITY CRITERIA

The Residential Care Programs, in order to determine the extent and nature of the residential care needs of severely physically handicapped persons of normal mentality, will provide residential care services to applicants selected by the program staff who meet the following eligibility criteria:

A. Residence: Sacramento County or Long Beach (Los Angeles County).

B. Age: Less than 65 years of age.

C. Physical Handicap: Applicant must:

   1. Have one or more severe, permanent handicaps that can be verified medically and that cannot be substantially eliminated through generally accepted medical procedures available in the area;

   2. Have a primary handicap other than blindness, deafness, or tuberculosis;

   3. Be so handicapped by his physical disabilities as to be dependent upon others for his daily care and well-being; and

   4. Be in reasonably good health to the extent that long-term hospitalization is not required.

D. Normal Mentality: Applicant must not be retarded or mentally ill to the extent that he would qualify for institutional care services of the California Department of Mental Hygiene.

E. Need Residential Care Services: Residential care services must be needed to alleviate a substantial impairment to the normal functioning of the individual or family unit. Financial need is not a criteria for eligibility. However, the resources of an individual must be fully utilized before program funds can be used.

F. General:

1. Applicant (or his guardian) must apply for services, must agree to participate and cooperate in providing any information required for this study, and must sign necessary applications and authorizations.

2. Residential care services will continue to be provided during the duration of this study as long as the client continues to meet the above eligibility criteria, he benefits from these services and the provision of these services yields the information needed for study of residential care needs.

APPENDIX D

THE NATURE AND EFFECT OF SELECTED HANDICAPPING CONDITIONS

In capsule form it is impossible to give a complete or entirely accurate description of any one of the conditions listed. Individual cases of each may vary widely in severity. All result in permanent disability which may or may not become progressively worse. Persons with very mild forms of these conditions are not likely to need the assistance described in this report. However, those with severe forms are likely to need some sorts of assistive devices in order to live at all. They must spend their lives either in wheelchairs or in beds and are constantly dependent for care upon others. Sooner or later most of them need financial assistance because of their inability to make a living and because of the great expense of their care. At sometime most of them need all or part of the special services described in this report. It is with those suffering from the more severe forms of these and many other equally crippling conditions that this report deals.

ARTHRITIS

Characteristics - Painful inflammation of the joints, with some destruction of the joints and adjacent bones, and resulting deformities. The disease may start at any age, but most often between 25 and 55 years of age. Known causes include infection, injury and degenerative joint disease.

Handicaps - Impairment of ability to walk or use arms, hands, fingers, with consequent limitation of activities.

Prognosis - Generally the various forms of the disease cause continuing deterioration. Drugs, physical and occupational therapy, and mechanical devices may make the patient more comfortable.

Long-Term Care Needs - Continuing medical care and supervision, physical and occupational therapy, bracing and orthopedic surgery, training in activities of daily living and use of special equipment, help with housekeeping and personal care, transportation, et cetera.

CEREBRAL PALSY

Characteristics - Impaired control of movement with lack of control of some or all extremities, involuntary movements, lack of balance and body control. Usually associated with injury or illness at birth.

Handicaps - The nature and extent of the impairments vary considerably, and may include speech, vision, and hearing problems. Walking, and self-care may not be possible.

Prognosis - The condition itself is usually static, but handicaps may impair normal physical growth and development. Life expectancy may be near normal.

Long-Term Care Needs - Continuing medical supervision, with necessary physical and occupational therapy, orthopedic surgery, bracing, special education and training, social, psychological, and vocational counseling, help with personal care, et cetera.

MULTIPLE SCLEROSIS

Characteristics - Progressive destruction of the central nervous system from unknown cause, with loss of motor and sensory functions. The disease is characterized by early periods of partial recovery between increasingly severe attacks.

Handicaps - Extremely variable; between attacks there may be general and severe weakness with easy fatiguability, and frequently with numbness, impaired vision, speech, coordination and some tremor or paralysis.

Prognosis - Attacks may be frequent or infrequent, with years of relatively normal functioning between early attacks. Disability increases after each attack, although life span may be considerable. In rapidly developing cases the sufferer may be permanently confined to a wheelchair within months.

Long-Term Care Needs - Hospitalization may be required during severe attacks; at other times individual may need medical and rehabilitation care, psychological and social support, help with housekeeping and personal care needs.

MUSCULAR DYSTROPHY

Characteristics - Progressive degeneration of muscles, with resulting weakness, usually occurring first in childhood or youth. It is more common among males than females. The cause of the disease is unknown, but there is an hereditary component.

Handicaps - Increasing weakness with eventual loss of function in arms, legs, face and/or body, depending upon the particular form of the disease.

Prognosis - There is usually increasing disability and eventual death after five or more years. There is no effective medical treatment.

Long-Term Care Needs - Medical, psychological, and social support for patient and family. Physical therapy, special braces, mechanical aids and help with personal care are usually needed.

PARALYTIC POLIOMYELITIS ("POST-POLIO")

Characteristics - Paralysis of arms, legs, and/or chest and trunk resulting from infection of the spinal cord.

Handicaps - Loss of functional use of any voluntary muscles of extremities, neck and/or trunk. Normal physical growth and development may be affected if paralysis occurs during childhood.

Prognosis - Impairments are usually permanent although some functioning can be improved through early treatment and rehabilitation. With proper care and treatment life expectancy may be near normal.

Long-Term Care Needs - Continuing medical care and rehabilitation; physical therapy; mechanical breathing devices, braces, and other assistive equipment are often required; attendant care and help with activities of daily living, and social support are needed. With the widespread use of polio vaccine very few new cases of paralytic polio now occur, but for many more years to come, those crippled with the disease in the past will need care.

QUADRIPLEGIA

Characteristics - Paralysis of both arms and both legs, usually caused by damage to the spinal cord from injury or infection. Automobile and sporting accidents are common causes.

Handicaps - Extent and degree of disability varies, depends on the part of the spinal cord that is damaged and on the attitude and retraining of the patient. Some individuals may be able to use a wheelchair or walk with the help of crutches and attendants.

Prognosis - Impairments are permanent. Life expectancy may be near normal with proper care and treatment.

Long-Term Care Needs - Continuing medical and nursing supervision; training or retraining for patient and family in the prevention of respiratory and urinary infections, bed sores, and further disability from contractures or disuse of limbs. Ramps, lifts, and assistance with housekeeping, personal care, social, psychological, and financial problems are often needed.

APPENDIX E

SPECIAL STUDIES ON HOUSING

SPASTIC CHILDREN'S FOUNDATION

In September, 1967, the adult residential program of the Spastic Children's Foundation, Los Angeles, opened to provide long-term care for severely physically handicapped adults. As an example of an institution offering not only living quarters, but other residential care services including educational and vocational opportunities, this program was of great interest to the project staff. Two staff members of the Bureau of Chronic Diseases were given an opportunity to survey its operations six months after its opening and were invited to suggest ways to improve its service to residents.

The Spastic Children's Foundation's (SCF) adult program is institutional in character and is capable of accommodating 50 long-term residents over age 18. Both ATD and self-paying clients are accepted. Almost immediately after opening, the facility was filled and soon developed a waiting list of 100. Licensed as an Establishment for Handicapped Persons, the adult program has its own nursing staff, but shares other professional staff with the larger, day-care program for children operated in an adjacent building. Continuing medical supervision is provided by residents' private physicians. Occupational, speech and physical therapy are available on a limited basis. An extensive activity program including access to classes, sheltered workshops and working responsibilities within SCF is augmented, when possible, by excursions into the community.

The majority of the residents have cerebral palsy; some are mentally retarded. More than half require wheelchairs but 20 percent require no assistive devices. Speech and balance problems are common and most of the residents require assistance with personal care needs. Few of the residents have attempted to receive vocational rehabilitation and none are regarded as having work potential other than in a sheltered workshop situation.

At the time of the survey, the residents liked their new home; only 20 percent indicated they would prefer another type of housing arrangement. Before moving into the new facility, most of them had lived at home with their families. The residents were urged to function as adults and even encouraged to consider less dependent living arrangements, e.g., group living. The program was operating reasonably well, but problems of staff quality and funding were not yet resolved. Volunteers were essential to supplement the paid staff and the current ambitious operational pattern was likely to cause large deficits.

The SCF adult unit offers a type of residential care satisfactory for certain of the handicapped and perhaps some other similar facilities are needed elsewhere in the State. It provides considerable emotional security to the handicapped person and his family - insurance for the future. The program answers the need to provide an enriched, specialized living arrangement for handicapped adults who are unable to live independently and who want to live with fellow residents equally disabled. It does not provide an answer to residential care needs acceptable to the majority of mentally normal, but physically handicapped people. Most of the Pilot Project participants would not accept this type of living situation willingly.

FRATERNITY HOUSE

A victim of an accident eight years ago, Jim Brown wanted to live independently of his family. He had completed high school and several years of college and, although he required an attendant to help him in activities of daily living, he was an able and interested student. With strong family support he anticipated pursuing further education. His family approached the project to see if guidance and funds could be made available to help them establish a "fraternity-type" setup for their son and several other handicapped college men, where they could live with their attendants. The family did not reside in Long Beach and therefore was ineligible to become part of the study group. The project recognized, however, that the residential care needs of college students deserved attention and permission was given to offer assistance in this residential experiment using funds from another source.

Locating permanently disabled young men to share this "fraternity house" was undertaken. Public agencies contacted students who might qualify. Health agencies provided guidance concerning the physical accommodations and recommended necessary structural changes to accommodate these handicapped persons.

While the staff was working to coordinate efforts toward the Browns' residential goal, the family was active. They organized an open house, placed articles in journals read by the handicapped and took care of many other details. A number of prospective residents were located but some felt the situation involved a risk; they were accustomed to living in more sheltered situations and were afraid to take the chance.

Transportation to the San Diego campus proved an obstacle. Attendants were needed and it was expected that they could be recruited from among able-bodied college students. This did not materialize. Concerns related to medical attention along with dietary management and housekeepers were expressed by some staff from local agencies. Jim Brown himself worked to develop rules and regulations related to the fraternity house and a tentative budget was drawn up taking into consideration the variations in assistance grants and the possibility that some residents might move out.

The "fraternity house" trial had assistance from voluntary and public agencies, support from an advisory group, support from a medical social worker on the pilot project and tremendous enthusiasm and support from Jim Brown and his family. However, it did not attract residents immediately and, as a result, there were insufficient funds to keep it going. An emergency fund from the San Diego Easter Seal Society helped with the first month's rent and the purchase of laundry equipment, but these funds were limited and could not keep the house open until there were enough residents to cover the costs.

The Pilot Project staff believes the concept of this type of group living to be sound. It was evident, however, that time and commitment of a professional staff are required to organize such a residential setting so that prospective residents have a stable, well conceived living situation. If such a venture is to succeed, there must be flexibility in attitudes and commitments of support from many people, agencies and organizations. The experiment in question lost momentum when the professional staff attempting to help the family encountered "red tape" that delayed action until almost the beginning of the school year. Similar experience has prevented or preemptorily ended other experiments in residential care.

Interviews with college personnel elsewhere in California confirm that some academic institutions have created apparently suitable living quarters in dormitories, infirmaries or apartments, but these fall far short of meeting the need for living facilities for handicapped college students.

GROUP LIVING

A group of handicapped veterans from a Veterans' Administration Hospital elected to try an independent living situation near the hospital in which they had met and were being treated. One man, a spirited and capable organizer, determined that five quadriplegics, with the pooled money they received as disabled veterans, could share a large, older apartment and hire two attendants and a cook-housekeeper. The men were of varying backgrounds and temperaments, but were all willing to try independent living. Hospital, medical and social services encouraged the venture. Since one resident had a car, transportation to the hospital and for excursions was available. For six months the arrangement worked reasonably well, even though some attandants hired by the group were unreliable and episodes of stealing money and furnishings, and even of assault on one of the group, occurred. Simple rules of the house hampered no one; the attendants worked in shifts; meal planning was sensible with foods purchased in quantity and at wholesale prices.

The project staff became interested in this living arrangement because it held such promise for other handicapped persons. It provided nursing care for the group, essential because several of them had developed pressure sores or experienced problems with catheters. Staff found the apartment to be substandard and inadequately heated. Working with the local health department, they were able to obtain adequate heat and sanitation. Additional service needs were minimal.

A series of events altered the relatively sound arrangement. The organizer had to return to the hospital because his physical condition required prolonged attention. Plumbing problems identified by the residents were neglected by the landlord until a health department inspector made an official complaint. Some of the residents, lacking the inner strength to supervise the attendants, left the apartment for other living situations.

The experiment survived all of this turmoil and when the Pilot Project ceased providing services in July, 1968, this group living arrangement was still functioning with three instead of five residents. Even those who had withdrawn continued in some form of independent living arrangement. All participants in this venture agreed that independent living arrangements were much preferable to hospitalization. Satisfaction with this living arrangement for the residents varied from one day to the next, often depending upon a relatively minor problem such as meals or attitudes of attendants. This was considered normal for a group of people living in a confined area. The project believes that this type of enterprise can succeed with adequate leadership and a certain amount of outside supervision.

A second opportunity to observe the benefits and hazards of group living was afforded the project staff by five persons living together in a nursing home. All five were confined to respirators and to bed in a nursing home geared to custodial care of the elderly and dying. Discontented, they plagued and antagonized the nursing home staff, adding to their own discomfiture. At the time the project intervened on their behalf, they were depressed nearly to the point of suicide. Tangible services provided by the project staff were few but meaningful: arrangements for two excursions away from the nursing home; arrangements for an art teacher to come in weekly; purchase of special equipment to turn book pages for a bedridden patient. Another more mobile handicapped person was brought in at frequent intervals to visit and to perform minor tasks for the residents. These visits proved therapeutic for all concerned. More important were the weekly counseling sessions by project staff, both with individuals and the group, giving them an opportunity to express their feelings and to consider alternatives to their present living arrangement. With a willing listener, who had the professional competence to bolster inner emotional strengths, the group found outlets other than antagonizing the nursing home staff and began to work toward individual aspirations.

There is little chance that these five people will ever live elsewhere than in a very protected environment. They could be separated from the elderly in the nursing home or moved to another institution housing younger people. The project showed that even in their present circumstances their outlook on life could be greatly improved with the expenditure of some professional thought and time and very little money. For the residents, the project brought the "outside" in.